Understanding the perspectives of UK-based family members of people who have chosen to end their life by assisted dying

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Abstract

Assisted dying is growing global momentum as an option to end unbearable suffering in particular medical circumstances, but remains illegal in the UK. Currently, UK citizens wishing for an assisted death must go to Switzerland; the only country to offer this service to non-citizens, but it is expected, by law, that family members do not facilitate this. This study sought to understand the perspectives of UK-based family members of people who have had an assisted death on assisted dying, to understand the contexts informing these perspectives, how they might connect with prior views on death and dying and the resources that they draw on during this period. Semi-structured interviews were conducted with five family members. This data was analysed using Interpretative Phenomenological Analysis, revealing four themes (A life dictated by illness, Life as autonomous, Navigating an “illegal” landscape and Assisted dying should be legalised). The results showed that family members felt there was a role for assisted dying in particular contexts related to experienced or pre-empted unbearable suffering associated with a medical diagnosis, and/or when the individual felt ‘ready’ to die. These perspectives appeared to be informed by views around the importance of autonomy and choice, the perceived importance of independence and the burden associated with being cared for, and experiences of navigating the process in the current UK context. Participants also shared what has helped them during this time (e.g. maintaining life as usual, connecting with close others and new hobbies). It is hoped these results can contribute to the current debate about the legalisation of assisted dying in the UK, to relevant policies should the UK legalise assisted dying, and to care considerations for tailoring support offered to individuals and families at times when an assisted death may be considered. Further research is needed to understand a wider range of perspectives within the UK on this topic.

Chapter 1: Introduction

1.1 Chapter overview

This chapter will describe how I arrived at this research topic, my position as researcher, and the epistemological stance informing this research. I will discuss the use of language in this study and share some relevant context in which this research is situated. Finally, I will critically appraise the relevant existing literature before presenting the rationale and aims for this study.

1.2 Arriving at the Research Topic

Working in various physical health contexts, I have witnessed the intractable suffering experienced by many people living with chronic and/or degenerative physical health conditions. I have connected with dilemmas about the meaning of life and death, what life without quality of life might mean, and with my clients, often surrounded by 'experts', this has prompted particular ethical questions, such as *who* has the power to define what quality of life means for them? I have also reflected on the dissonance between the oath taken by doctors to 'do no harm' and the expectation that medical interventions will relieve suffering (Cassell, 1992), with the focus of our National Health Service (NHS) in the United Kingdom (UK) to mitigate suicide and keep people alive, whatever the context (Department of Health and Social Care, 2019; NHS, 2019). Masel (2022) questions whether medical professionals should prioritise this preservation of life or focus on maintaining patient autonomy; something that is privileged in a westernised approach to healthcare (Goldberg et al., 2021). As such, I have been left wondering; can death ever be a therapeutic goal (Masel, 2022)?

As people, connected by social networks, I have also considered who else might be affected by an individual's living, quality of life, and suffering. In my work, I have met with many family members who are companions on these journeys of suffering (as this is often when we, as Psychologists, join families on these journeys), and acknowledge their valuable contributions to all stages of the journey. For this study, I was drawn to the experiences of family members living alongside this often unbearable suffering, and subsequently, what their perspectives might be when their loved one enduring this suffering chooses an assisted death. I considered the layers of relationship one might hold with death itself and the added moral, social, and ethical complexities that assisted dying brings, particularly after a context of unbearable suffering. I have wondered about the multitude of contexts that might inform these perspectives. I have also considered what grief might look like in the context of an 'illegal' death (see section 1.6.3), and as a result, whether family members in the current UK context want to and/or are able to access appropriate support during this time.

Tracy (2010) discusses what makes a topic 'worthy' of being researched and names four criteria: 'relevant', 'timely', 'significant' and 'interesting'. Whilst the latter two may be more subjective, this research feels particularly relevant and timely given the current debates around the legalisation of medically assisted dying in the UK (see section 1.6.3). It feels crucial that all voices are heard in this debate, and I see this research as an opportunity to contribute family members' perspectives to these conversations, given the multitude of ways they may be impacted by unbearable suffering and the assisted death itself.

1.3 Position of researcher

Reflexive practice is important in qualitative research in order to strengthen the understanding of research outcomes (Mitchell et al., 2018). It involves consideration of the researcher's position, their world view, and their influence over the knowledge gathered, and its interpretation (Berger, 2015; Greenbank, 2003; Savin-Baden & Howell-Major, 2013). Transparency around this holds researchers accountable for the research process, potential influences on findings and as such, increases the credibility of these findings.

Consideration of whether the researcher is an 'insider' researcher (someone with shared experience of the phenomena being researched) or an 'outsider' researcher (someone without this experience; Berger, 2015; Teh & Lek, 2018) is therefore necessary. This is particularly relevant when considering power within the researcher-participant relationship (Grove, 2017), and the role of the researcher (who has ownership over study outcomes) in asking participants to share their experiences, despite lacking this control (Dodgson, 2019).

Reflecting back over my research journey, I note that initially I felt that I was an ‘outsider’ researcher. I did not ascribe to being able to fully empathise with the participants’ experiences, despite holding personal connections to this topic. However, over time, I noticed this position shift. Deutsch (1981) described positionality as an evaluative process, rather than a static position; suggesting that a researcher’s position may change in relation to the experiences of conducting the research itself. I noticed this shift myself and began to connect with what has been described as the ‘other’ research position (Heath, 2018; Herod, 1999). Whilst I still felt that there were many aspects of the participants’ experiences that I did not share, similarly to Heath (2018), I began to connect with aspects of my experience that did not connect with the ’outsider’ research position. This included my clinical experience of working with people significantly suffering as a result of their physical health, and their families, as well the knowledge I hold about assisted dying as a result of knowing individuals who have chosen this way to die. As I became more connected with these experiences through the research process, I became aware of this shifting position and used supervision and my reflective diary to consider the impact(s) this may have on my relationship with this research (e.g., whether I was privileging certain information that resonated with my experiences). Further reflections are shared in Chapter 4.

1.4 Epistemological position: A critical realist perspective

Researcher positionality, ontology, and epistemology were considered in relation to the study design and the impact they would have on the data collected and findings of the research (Moon & Blackman, 2014). I noted my belief that a reality exists outside of human perception or observation; and therefore, that death and suffering form part of reality, and subsequently; that assisted deaths can provide an end to this suffering, when it becomes unbearable. I also believe that our experiences of the world are constructed through observation, with differences in these observations reflecting individuals experiencing different parts of reality and being influenced by their contexts and experiences (Warwick, 2020). I note that this leaves us unable to ever truly capture the complete reality of the world.

As such, a critical realist stance was chosen as the epistemological lens for this research, as this fit with my beliefs about there being entities that exist outside of our knowledge or complete understanding (Fleetwood, 2005). As a result, this research focused on understanding how people experience their reality and the meaning they make from these experiences, rather than expecting to capture reality itself. Conscious of the many narratives in healthcare provision around the ‘realness’ of symptoms, and actively striving to not collude with the notion that it is *“all in their head”* (Hintz, 2022), I wanted this research to take the stance that suffering (in whatever form it takes) is real. However, I wanted to also recognise, and contextualise, the subjectivity in an individual’s known ‘reality’, through gaining an understanding of their contexts. This felt particularly important, given the nature of experiencing ‘unbearable suffering’ (extensive suffering specific to an individual that has medical, psychological, social, and existential dimensions) being a recognised pre-requisite for being granted access to an assisted death (Dees et al., 2010).

1.5 Use of Language

The terminology associated with assisted dying (i.e., medically facilitated end of life) is multifaceted and includes legal, medical, personal and philosophical languages (Masel, 2022). The official terms used to describe this differ cross-culturally and are also specific to the method used to facilitate death (Mroz et al., 2021).

This study will make use of the terms ‘assisted death’ and ‘assisted dying’ when referring to medically facilitated end of life (see section 1.5.1). It is acknowledged that these terms may not fit for all people affected by assisted deaths, and/or in all countries, and therefore other terms are used at various points as appropriate.

Reflexivity (the understanding that a researcher's assumptions, experiences, and contexts can influence all aspects of research), and the need to acknowledge and consider the influences these biases might have, has been identified as an important quality indicator in research (Johnson et al., 2020). Therefore, whilst the majority of this thesis is written in the third-person perspective, for authenticity, the first-person perspective has been used when sharing my own reflections as the researcher.

1.5.1 Assisted death

The term 'assisted death' is used to refer to the act of intentionally helping someone to end their life, at their request, and encompasses Euthanasia (sometimes described as 'Voluntary-Active Euthanasia' to highlight the voluntary nature) and Physician-assisted suicide (Fontalis et al., 2018). Euthanasia, in this context, is the act of a clinician deliberately ending the life of a patient through medical means (e.g., by administering a fatal dose of a drug to the patient), while physician-assisted suicide involves a medical clinician prescribing a patient with life-ending drugs, for the patient to administer themselves (Government of Netherlands, n.d.; Radbruch, et al., 2016; Tucker & Steele, 2007).

1.5.2 Unbearable suffering

The term 'unbearable suffering' (otherwise known as 'intolerable' suffering in Canada; Landry et al., 2015) is often named as the critical reason someone may request an assisted death, however it is ill-defined within the literature, given the lack of objective measurement. Nevertheless, Dees and colleagues (2010) have attempted to define it as *"a profoundly personal experience of an actual or perceived impending threat to the integrity or life of the person, which has a significant duration and a central place in the person's mind".*

It is widely agreed that it must be the individual that concludes that their suffering is ‘unbearable’ based on their circumstances and sense of their ability to cope. The medical consultant in charge of granting permission for the assisted death needs only to be persuaded of this (Buiting et al., 2008).

1.5.3 Family member

In this research, the term ‘family member’ is used for anyone that identifies in this way in relation to the individual who has had the assisted death. There is no requirement for this to be related to biological parameters or relationship status; moving beyond the notion of ‘nuclear family’ (Saggers & Sims, 2005). This fits with a systemic perspective of ‘family’ as a self-defined group of people who feel connected in this way, without formal identification of this connection being required (Whall, 1986). Further details about how this fits with the study’s eligibility criteria are detailed in section 2.3.2.

1.6 Locating the research

This research is located within the UK, where at the time of writing, it is a criminal offence to encourage and/or assist someone to end their life (see section 1.6.2). Therefore the outcomes of this study are specific to the UK, in this context, and are not intended to be generalisable cross-culturally.

This research was also undertaken after the peak of the Coronavirus (Covid-19) pandemic, which disproportionally affected particular groups of people, including those with ongoing health and caring needs (UK Parliament, 2022a). During this time, due to government guidance around ‘social distancing’, in an attempt to reduce virus spread, medical and care support services were restricted. This may have impacted the support received by individuals living with chronic and/or deteriorating physical health conditions, alongside others. Furthermore, whilst the UK government reported that the imposed travel restrictions during ‘lockdowns’ did not include those wishing to travel abroad for an assisted death (BBC, 2020), rules imposed around isolating and the restrictions of gatherings are likely to have impacted the ability for families to come together through a loved one's assisted death journey. It is possible, for participants in this study, that living through the effects of the pandemic impacted their loved ones' unbearable suffering and/or their decision for an assisted death.

1.6.1 Assisted dying around the world

The UK and its current position on assisted dying is situated within a wider global context. Currently, a small but ever-increasing number of countries have legalised assisted dying (in some form), and global support of assisted dying appears to be increasing (Mroz et al., 2021; Roehr, 2021). Most recently, Portugal passed legislation to legalise 'Euthanasia' in certain contexts, which is expected to come into effect later this year (BBC, 2023; The Portugal News, 2023). Furthermore, all states in Australia have now approved 'Voluntary assisted dying'; with Victoria and New South Wales due to implement these laws this year (End of Life Law in Australia, 2023). Figure 1 illustrates the countries that currently permit a form of assisted dying and the year it was legalised.

Mroz and colleagues (2021) report that, at the time of publication, assisted deaths generally made up between 0.1 and 2.1% of deaths in countries where it is legal. However, this rate has been reported to be somewhat higher in Canada (where 'Medical Assistance in Dying' accounted for 3.3% of deaths in 2021; Government of Canada, 2023; Statista, 2022) and the Netherlands (where 'Euthanasia' accounted for 4.5% of deaths in 2021; Statista, 2022; The World Federation of Right to Die Societies, 2022). It has been suggested in the media that increased rates of assisted dying may be because it is becoming *"too easy"* to access these services (The Guardian, 2019; The New York Times, 2022) or because there is an *"increased awareness and greater acceptance"* of assisted deaths in particular medical situations (CTV News, 2021).

It has been identified that typically, people accessing assisted deaths are older (approximately 60-85 years old), racialised as ‘White’, identify as male and are deemed to be highly educated (Emanuel, et al., 2016; Steck et al., 2013).

In all countries where assisted deaths are legal, there are strict protocols surrounding processes to ensure *“due care”* is adhered to (Government of Netherlands, n.d.). This includes the individual needing to meet specific eligibility criteria (e.g., being able to provide informed consent, and meet the country-specific criteria around the nature of their condition). It also requires the responsible clinician to abide by country-specific safeguarding procedures to ensure this *“due care”* (Emanuel et al., 2016; Mroz et al., 2021). However, the specific type of assisted death that is legal and the term used to define it differs between countries. For example, Canada uses the term ‘Medical Assistance in Dying’ (Government of Canada, 2023; Holmes et al., 2018) whereas Australia uses the term ‘Voluntary Assisted Dying’ (Close et al., 2021; End of Life Law in Australia, 2023). Further details of these differences globally are detailed elsewhere (e.g., BMA, 2021; Mroz et al., 2021).

Figure 1 – Timeline of legalisation of assisted dying around the world

1942 – Switzerland

1997 – Oregon (USA)

2002 – Belgium; Netherlands

2008 – Washington (USA)

2009 – Luxembourg; Montana (USA)

2013 – Vermont (USA)

2015 – California (USA); Germany

2016 – Canada; Colorado (USA); Washington DC (USA)

2018 – Hawaii (USA)

2019 – Maine (USA); New Jersey (USA); Victoria (Australia)

2021 – New Mexico (USA); New Zealand; Spain; Western Australia (Australia)

2022 – Colombia; Tasmania (Australia)

2023 – New South Wales (Australia); Portugal; Queensland (Australia); South Australia

1.6.2 The UK: Cultural perspectives of death and dying

The UK's position on assisted dying is also situated within its wider cultural relationship to death and dying more generally. Whilst it has been reported that more than half a million people die in the UK every year (Sleeman, 2013; Statista, 2023), the UK, alongside other countries in the western world, has been associated with a culture of 'death denial' with talking about death and dying often being seen as 'taboo' (Tradii & Robert, 2019; Walter, 2017; Zimmermann & Rodin, 2004). This has seemingly encouraged many to embrace a 'live forever' mentality, discouraging open conversations on these topics (Kirshbaum, Carey, & Conrad, 2011). This is exemplified in the language commonly used in the UK around a death (e.g. saying that someone has 'passed' or has been 'lost') that is seemingly detached from the significance of this life event that has taken place.

Furthermore, conversations around death and dying are often left to medical professionals, who acknowledge their own avoidance of these conversations due to *"not want[ing] to upset patients"* (Kirshbaum, Carey & Conrad, 2011) or to take away a sense of hope (Sleeman, 2013). This may be because a death in these contexts could be viewed as a 'failure' of the medical profession to do more (Sleeman, 2013). These struggles to have open conversations around death and dying have been identified to impact the quality of healthcare provision for both the dying individual and their loved one(s) (Seymour et al., 2010).

Alongside this culture of death denial, many in the UK may subscribe to an individualist perspective of the journey of life and its end that is often perpetuated within the west (e.g., a belief that an individual controls their own destiny; Seymour et al., 2010). Assisted dying, therefore, may align with this view as it offers the opportunity for an individual to choose and have control over the end to their life.

1.6.3 Assisted dying in the UK

Whilst access to assisted dying is increasing globally, and although it is legal in the UK to travel abroad for assisted death (UK Parliament, 2020), assisting or encouraging someone to die (including accompanying someone to have an assisted death outside the UK) remains illegal. This can result in a maximum penalty of 14 years imprisonment under the Suicide Act of 1961 in England and Wales and the Criminal Justice Act of 1966 in Northern Ireland. In Scotland, assisting someone to die is not a crime but could result in prosecution for culpable homicide (Crown Prosecution Service, 2014). As a result, UK citizens wishing for an assisted death are expected to travel abroad, without their loved ones, which has been described by some as 'suicide tourism' (Gauthier et al., 2015; Gürcü et al., 2016; Richards, 2017).

At the time of writing, these UK citizens must travel to Switzerland, the only country to offer this procedure to non-residents (Caruso et al., 2019; Goh et al., 2022). In Switzerland, the term ‘accompanied suicide’ is used to describe an assisted death (for both Swiss citizens and foreign nationals accessing these services; Dignitas, 2023a). It is estimated that on average, up to fifty British people travel to Switzerland for an assisted death annually (Dignity in Dying, 2020).

Despite the legal status, however, prosecutions surrounding assisting or encouraging someone to die have been rare in recent years. The Crown Prosecution Service (CPS) states that between April 2009 and the end of March 2023, only 182 of these cases were referred to the CPS, with 125 of these not being progressed by the CPS and 35 being subsequently withdrawn by the police. Only four prosecutions were made during this time (Crown Prosecution Service, 2014). This is likely due to current legal guidance requiring prosecutors to consider whether or not prosecution is in the public interest (Crown Prosecution Service, 2014). As a result, it has been questioned whether assisted dying has become de-facto decriminalised in the UK (Hurford, 2020), suggesting that the UK landscape around assisted dying may be changing.

Furthermore, a recent motion passed in 2021 by the British Medical Association (BMA; an association made up of doctors and medical students), showed a shift from the BMA previously opposing assisted dying, which had been in place since 2006, to now taking a ‘neutral’ stance on it. This indicates that they will now neither support nor oppose a change in law. Additionally, the UK government’s Health and Social Care Committee is currently conducting a national inquiry to explore different perspectives about the possibility of legalisation within the UK, which includes reviewing submissions from the UK public to inform ongoing decision making (UK Parliament, 2022b). Following an initial review of the literature for this thesis, I was able to contribute to this (see section 2.5 for further information).

1.6.4 Accessing an assisted death in Switzerland

Alongside offering non-residents access to assisted dying services, Switzerland is one of few countries in which the primary criteria for having an assisted death does not require the unbearable suffering to be a consequence of a physical health diagnosis (Hodel et al., 2019). To access an assisted death in Switzerland, individuals are only required to have decision-making capacity and ‘control’ over their death (i.e. be able to administer the lethal medication themselves; Dignitas, 2023a; Pegasos, n.d.). Article 115 of the Swiss Penal Code in Swiss law permits assisting someone to die as long as the motives of the person providing assistance are deemed to not be ‘selfish’ (The Federal Council, 2023).

Assisted deaths in Switzerland are usually coordinated by non-government ‘right-to-die’ organisations (Hodel et al., 2019). Four of these organisations (e.g. Dignitas; http://www.dignitas.ch/) offer assisted deaths to foreign nationals alongside Swiss citizens (Gauther et al., 2015). Accessing an assisted death at one of these organisations usually takes around three months from initial contact, following a process which is detailed elsewhere (e.g. Dignitas, 2023a). As the lethal medication must be prescribed by a medical doctor, Dignitas requires that the individual provides relevant medical documentation as proof of a *“terminal illness and/or unendurable incapacitating disability and/or unbearable and uncontrollable pain”*, alongside other documents, to be able to access the service (Dignitas, 2023a). The documentation, alongside at least two meetings with the responsible doctor, offers the opportunity to understand whether the individual has considered all alternative options for relieving this suffering, to assess decision-making capacity and ascertain that they are not being pressured into making this decision.

Whilst individual circumstances differ, it has been suggested that having an assisted death in Switzerland, at one of these organisations, costs UK citizens approximately £10,000, but can cost anywhere between £6,500 to over £15,000 (Dignity in Dying, 2017). Therefore, whilst most UK households have been reported to hold less than £10,000 in savings; this leaves these services currently inaccessible to a significant proportion of the population (Dignity in Dying, 2017; Independent, 2017).

1.6.5 Family members and assisted dying

It has long been acknowledged that living with a chronic and/or degenerative health condition, and the associated suffering, impacts family members as well as the individual (Covinsky et al., 1994; Golics et al., 2013; Patterson & Garwick, 1994). Family caregivers are often described as the *"backbone of the healthcare and support team"* (Goldberg et al., 2021), as they are required to take on a number of tasks to support a loved one such as; practical and emotional support, advocating for them, and coordination of their care (Cheung & Hocking, 2004; Eriksson & Svedlund, 2006; Gamondi et al., 2018). It has been identified that these can have detrimental impacts on family members over time, but that these needs are often neglected (Sherman, 2019). It has also been suggested that, if the cared-for individual chooses an assisted death, these responsibilities may increase (Gamondi et al., 2018; Starks et al., 2005).

An individual choosing to end their life by assisted death can be an understandably difficult decision for a family to adjust to. Family members may display a disparity of views around assisted deaths (Emanuel et al., 2000; Gamondi et al., 2018; Ganzini et al., 1998; 2006) and some may feel that there are other options still available that should be considered (Dees et al., 2013). Family caregivers may also need to negotiate difficult discussions around the decision, offer emotional support and aid with the organisation of supporting documentation (Fujioka et al., 2018; Gamondi et al., 2018; Kimsma, 2010; Kimsma & van Leeuwen, 2007; Starks et al., 2005), whilst also continuing to offer informal care to their loved one and navigating the impacts on themselves (Goldberg et al., 2021).

Some family members might escort their loved one to Switzerland for the assisted death, despite this remaining illegal in the UK (Gauthier et al., 2015; Gürcü et al., 2016), whilst others may have to navigate the impact of not being able to be present for their loved one's death (Dignity in Dying, 2017). Right-to-die organisations such as Dignitas encourage family members and/or friends to be present for the assisted death wherever possible. It is felt that this is important support for the individual accessing the assisted death as well as beneficial for the family member(s) / friend(s) themselves with the transition and grieving process (Dignitas, 2014).

1.7 Systematic Literature Review

1.7.1 Overview and aims

This section will present a Systematic Literature Review (SLR) relevant to the current study's scope and aims, intending to gather a comprehensive understanding of related literature and to highlight gaps in current knowledge (Fink, 2019). As the systematic search found no published literature from UK-based studies aiming to understand family members perspectives on assisted dying, this SLR was conducted to understand the views globally of family members of people who have had an assisted death.

The question of focus for this SLR is:

"What does the existing literature tell us about the views of family members of people who have had an assisted death"?

Whilst it is acknowledged that a similar SLR was undertaken in 2019 by Gamondi and colleagues, it still felt important to conduct this current review for a number of reasons. Firstly, the review by Gamondi and colleagues (2019) was based on the question *"what are family members' **experiences** of assisted dying"?* This focused on family members who had been part of the assisted dying process, explicitly excluding studies looking at attitudes to assisted dying where family members had not been present at the death. For this reason, they also excluded studies undertaken in places where assisted dying was not legal. Whilst the authors gathered valuable insight into family members' experiences of assisted dying, there was a case for conducting another SLR focused specifically on family members' *views* of assisted dying as an option, regardless of their explicit involvement in the assisted death itself. It was felt that this would offer a synthesis of knowledge of this research area, influencing developments within the field, particularly when countries are considering legalisation and subsequent policies around this. It was also felt that this would usefully inform this research, in which there was no requirement for family members to have been involved in the assisted death.

Secondly, the global landscape of assisted dying is everchanging. Since Gamondi and colleagues' study in 2019, significant changes have occurred globally. For example; New Zealand legalised assisted dying in 2021 (Ministry of Health, 2022) and there are currently ongoing developments around legalisation in Australia (End of Life Law in Australia, 2023) and Portugal (BBC, 2023; The Portugal News, 2023). It was therefore felt that this SLR should include papers published since 2019, alongside earlier papers, to ensure that a meaningful span of the literature and views available were included. As a result, this SLR includes papers published since 1942 (when Switzerland became the first country to permit assisted dying) to the current time (2023).

1.7.2 Search strategy

Four electronic databases (PubMed, Scopus, EBSCO and Psychnet) were searched via the University of Hertfordshire between January and March 2023. It was hoped that these databases would encompass literature from relevant disciplines across healthcare (e.g. applied social sciences, including psychology, medicine, nursing and social work). Alerts were set up on the databases to capture all relevant up-to-date papers ahead of the analysis stage.

The search strategy was informed by preliminary searches, to gain an understanding of the commonly used terms for assisted dying within the literature. These highlighted a variety of terms used for assisted dying around the world. The search terms were also cross-checked with a doctoral peer (particularly Concepts 1 and 2 that required less specialist knowledge of this topic; see Table 1). It was hoped that this would lead to the inclusion of a meaningful range of terms and aid reliability of search results. When appropriate, search terms were abbreviated to generate all relevant articles (e.g., child* = child or children). On each database, searches were first conducted separately for each concept using the Boolean operator ‘OR’ and then the results from the three individual searches were combined using the Boolean operator ‘AND’ to yield all papers from that database. Please see Table 1 for all search terms used.

Table 1 – Search terms used for SLR

Concept 1	**Concept 2**	**Concept 3**
Family member*	View*	“Assisted death”*
Famil*	Experience*	“Medical assistance in dying”
Relation*	Perception*	MAiD
Relative*	Attitude*	“Medical aid in dying”
Spouse*	Opinion*	“Accompanied suicide”*
Partner*	Feeling*	Euthanasia
Child*	Perspective*	“Assisted suicide”*
Carer*	Reflection*	“Physician-assisted suicide”*
Caregiver*	Belief*	“Medically assisted suicide”*
Friend*	Outlook*	“Family assisted suicide”*
Family member*	Mindset*	“Patient-directed aid in dying”
	Position*	“Patient-directed dying”
		“Voluntary-euthanasia”
		“Dying with dignity”
		“Aid in dying”

During the search process, it was identified that searches needed to be filtered (where possible on the database) by ‘human’ participants, as many studies about ‘euthanasia’ focused on animals. Given this study’s limited resources, and lack of access to interpreters, the search also focused solely on articles written in English. Table 2 clarifies the inclusion and exclusion criteria for this SLR. Similar to Gamondi and colleagues (2019), this SLR focused on papers which reported family members’ own words, not papers in which others spoke on family members’ behalf. Furthermore, only qualitative studies or studies with a significant qualitative element were included to ensure that family members' views, and relevant context informing these views, were adequately captured.

Decision making about which papers fitted the criteria of containing family members' *views* about assisted dying was a complex process. This involved the need to reflect on the nuance in the difference between an 'experience' (identified as a description of the facts of what happened) and/or a 'view' (identified as someone's perspective on the assisted death that took place and/or assisted dying more generally), and making a decision about whether a quote aligned with this definition of 'view'. These decisions were considered carefully and were supported by the guidance of supervisors and conversations with doctoral peers.

Finally, data was only included that reported views of family members after an assisted death had taken place (as opposed to those where assisted dying was being considered). This decision was made in the hope of capturing perspectives informed by the experience of knowing a family member that had an assisted death, rather than solely based on more general life principles; given the impact this lived experience may have on views (see Appendix A for reflections on this decision).

Table 2 – SLR inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Studies published since 1942 (inclusive)	Studies published before 1942 (exclusive)
Studies published in the English language	Studies not published in the English language
Studies using human participants	Studies about euthanasia in animals
Studies that include the views of family members' / caregivers' of people who have had an assisted death	Studies focused on the views of others (i.e., people in professional caregiving roles) or where the assisted death has not taken place
Studies with a qualitative component capturing firsthand views from family members	Quantitative studies or studies in which views of family members are shared by others (e.g., by a medical professional)

Once the searches had been completed, the next stages of the SLR were to:

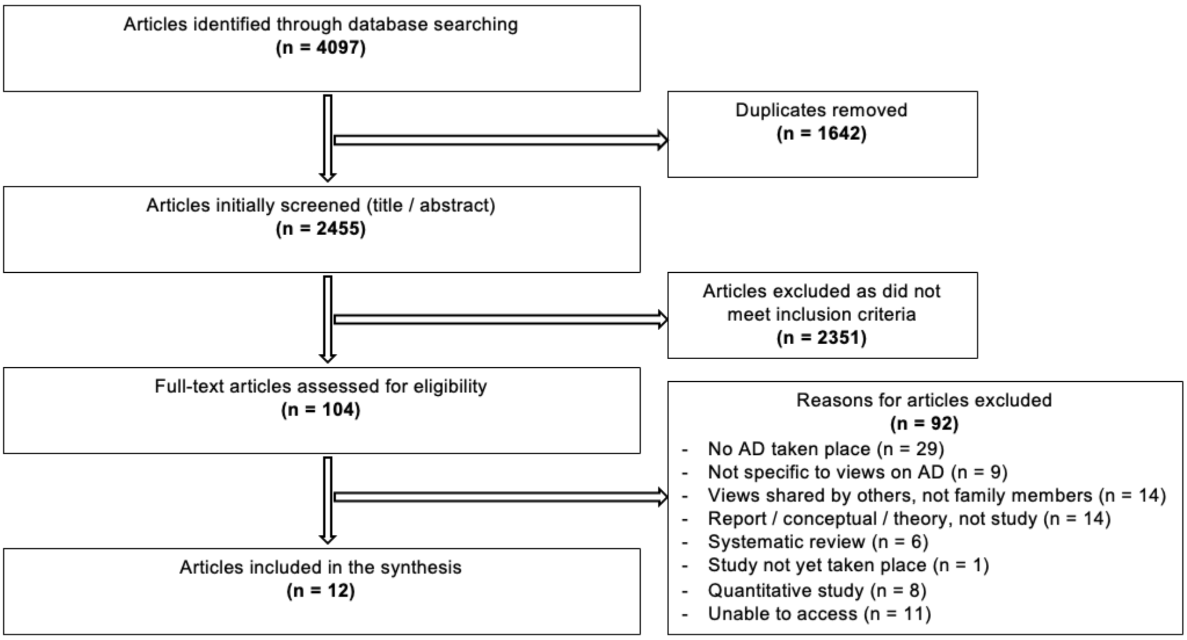
- Export search results from each database to reference management software.
- Remove any duplicate papers.

- Screen titles and abstracts of the remaining papers based on the inclusion and exclusion criteria, and remove any inappropriate papers.
- Review the remaining full text articles against the inclusion criteria.
- Hand-search the reference lists of the selected papers to check for papers that met the inclusion criteria.
- Review Google Scholar for any outstanding papers.

1.7.3 SLR results

The initial database searches identified 4097 papers. Once duplicates were removed (n = 1642), this left 2455 papers for title and abstract screening. Further papers were removed at this stage (n = 2351, based on the inclusion and exclusion criteria), leaving 104 papers for full-text review. At this stage, 11 records were unable to be accessed. Efforts made to access these records included utilising different online databases, via the University of Hertfordshire library and attempts to contact authors. Subsequently, 12 articles met the criteria for inclusion in this SLR (see PRISMA flow chart; Figure 2) and were included in this SLR. No additional papers were included from other sources.

Figure 2 – PRISMA flow chart illustrating SLR article selection process



The combination of selected studies offered views from four countries in which assisted dying was legal at the time the study was conducted (despite this not being in the inclusion criteria); USA (n = 2), Switzerland (n = 3), Canada (n = 6) and the Netherlands (n = 1). The data synthesised for the SLR incorporated family members' views on assisted dying generally, as well as views specifically related to their experience of their family member's assisted death. The term 'family member' in this SLR is consistent with how it has been defined for this study (see section 1.5.3). Eleven of the studies used a qualitative design and one study used a mixed methodology design. In the mixed methodology study, Snijdewind (2022) included sufficient qualitative data to meet the SLR inclusion criteria.

Four of the papers focused on family members' experiences of supporting their family member in the assisted dying process (Buchbinder et al., 2018; Gamondi et al., 2018; Holmes et al., 2018; Thangarasa et al., 2022), and one paper focused on experiences specifically related to interactions with professionals during this period (Gamondi et al., 2020). Five studies explored the impacts of assisted dying on bereavement (Beuthin et al., 2022; Gamondi et al., 2015; Laperle et al., 2022; Snijdewind, 2022; Srinivasan, 2019). Two papers were service development studies, evaluating the care offered at an assisted dying service (Brown et al., 2022; Hales et al., 2019). Despite the various foci of these studies, all papers detailed views of family members on assisted dying from these various lenses. These were collated for this SLR, in line with the SLR question. A summary of these studies can be found in table 3[1][2].

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[1] Please note that the range of terms used for assisted dying in this table match those used in the paper itself (usually the term used in the country in which the research was conducted).

[2] Studies are cited in this table in the order in which a form of assisted dying was legalised in the region of publication (as per Figure 1).

Table 3 – Summary of included studies

Title, author(s), year of publication, country	**Aim(s)**	**Participants**	**Data collection method**	**Data analysis method**	**Key findings**	**Strengths and limitations**
Exploring the experiences of bereaved families involved in assisted suicide in Southern Switzerland: a qualitative study. Gamondi, Pott, Forbes & Payne (2015) Switzerland	To understand the involvement of family members in the assisted suicide process and understand ways of coping with bereavement of this type.	11 relatives of people who had assisted suicide.	Semi-structured interviews	Principles of Grounded theory	Bereaved family members of people who have an assisted suicide are faced with moral dilemmas, feelings of isolation and secrecy in managing the assisted suicide; which are all interconnected in their impact.	**Strengths:** - Qualitative research design is appropriate to explore experiences of participants - First author owns positionality - Sample included approx. equal split of men and women - Stated reasons why people declined to take part - Included individuals with different relationships to the family member that had an assisted suicide **Weaknesses:** - All individuals who had an assisted suicide had a cancer diagnosis which may limit generalisability - Unclear analysis framework - Unclear if ethical considerations were addressed
Family Caregivers' Reflections on Experiences of Assisted Suicide in Switzerland: A Qualitative Interview Study. Gamondi, Pott, Preston & Payne (2018) Switzerland	To explore Swiss family caregivers' reflections on experiences of assisted suicide.	28 family carers of people who died by assisted suicide.	Interviews (face-to-face)	Qualitative content analysis / Framework analysis	Family involvement in assisted suicide was categorised in five phases; 1. Contemplation, 2. Gaining acceptance 3. Gaining permission 4. Organisation 5. Aftermath Participation in each stage varies and is impacted by the illness experience of the person choosing an assisted suicide, their awareness of approaching death, the family member's awareness of that person experiencing unbearable suffering and the emotional / practical impact on family member of being involved in the assisted suicide.	**Strengths:** - Qualitative research design is appropriate to explore reflections / experiences of sample on under researched topic - Participant sample covered a range of family relationships to the individuals that had an assisted suicide - Participants' comfort was considered for interviews - Clear analysis method - Researchers considered potential biases they brought and implications these had for the study **Weaknesses:** - Lacking detail about recruitment process - Not clear *how* researchers accounted for possible bias - No disclosure of what the researchers' personal relation to topic is its possible impacts - Not clear how the study was explained to participants

Swiss Families' Experiences of Interactions with Providers during Assisted Suicide: A Secondary Data Analysis of an Interview Study. Gamondi, Pott, Preston & Payne (2020) Switzerland	To explore Swiss family members' experiences / reflections of assisted suicide, particularly in relation to interactions with professionals during this time.	28 family members / close friends of people who died from assisted suicide	"In-depth interviews" – appear to be semi-structured through the use of a topic guide.	Secondary analysis of qualitative data from previous study Framework analysis	Identified two main themes associated with interactions with professionals: 1. Interactions concerning assisted suicide 2. Choices about disclosing their experience of assisted suicide It was noted that interactions may have different uses to family members depending on whether they are with healthcare professionals or professionals from right to die organisations.	**Strengths:** - Makes use of data already available, considering the sensitive nature of the topic and impact further interviews may have on participants - Names that the researchers consider reflexivity in research practice important - Clear analysis method - Two researchers involved in analysis process for inter-rater reliability - Followed recognised guidelines for quality assurance **Weaknesses:** - Lacking detail about recruitment process - Unclear if ethical considerations were addressed - Specific to certain parts of Switzerland, questions around generalisability
Bereavement and the Oregon Death with Dignity Act: How does assisted death impact grief? Srinivasan (2019) USA (Oregon)	To explore bereavement experiences following an assisted death	22 family members of people that had an assisted death.	Individual interviews	Thematic analysis	Five themes were established related to the experience of grief following an assisted death: 1. General grief reactions 2. Anticipating the death 3. Sense of control 4. Level of agreement with assisted death Grief expression and stigma.	**Strengths:** - Collected demographical information about religious beliefs - Clear recruitment strategy - Clear analysis method **Weaknesses:** - Not clear if ethical approval was received - Researcher does not own position or consider biases that might influence research - Structure or content of questions asked at interview not included
"I lost so much more than my partner" – Bereaved partners' grief experiences following suicide or physician-assisted dying in case of a mental disorder Snijdewind (2022) Netherlands	To understand the experience of losing a partner via a physician-assisted suicide (PAD) or suicide in the context of mental health struggles.	17 bereaved partners of people who died by PAD or suicide.	Survey (including the Grief Experiences Questionnaire) and semi-structured interviews.	Quantitative: descriptive analyses, chi square tests, independent t-tests, multiple regression Qualitative: Thematic analysis	Partners bereaved by suicide and PAD don't feel understood by others, but challenges vary depending on type of death; partners of those who died by PAD feel more prepared to undertake necessary decision making (due to being supported by the associated physician) whereas those bereaved by suicide feel less prepared to make the required decisions following the death.	**Strengths:** - Valuable contribution to the literature given its focus of the impact of these types of death after mental health rather than physical health struggles - Valuable contribution to the literature in comparing impacts of assisted and non-assisted suicide on family members - Variety of recruitment methods used + clear strategy detailed

						- Range of demographical information collected - Clear analysis method - Multiple researchers involved in analysis increases inter-rater reliability **Weaknesses:** - Researcher does not own positionality or discuss impact of potential biases on research
Caregivers' Experiences With Medical Aid-In-Dying in Vermont: A Qualitative Study. Buchbinder, Ojo, & Brassfield (2018) USA (Vermont)	To understand the experiences of non-professional caregivers who were present during medical aid-in-dying (AID).	19 caregivers of people who died using AID.	Semi-structured interviews (face-to-face)	Secondary analysis of qualitative data from wider study Inductive iterative approach (informed by grounded theory)	Social support provided by caregivers during an AID death falls into two broad categories; emotional and instrumental and within four temporal phases; preparation, ingestion, waiting, and after death. The needs of the dying person were prioritised over the caregivers' own emotional responses.	**Strengths:** - Qualitative research design is appropriate to explore experiences of sample on under researched topic - The inclusion of multiple family members for some assisted deaths offers an understanding of different perspectives on the same death - The researcher considered the impact of positionality and attempted to address this by naming their neutral position at beginning of interviews - Multiple coders and blind coding at analysis stage increases trustworthiness of findings - Utilisation of secondary data viewed positively **Limitations:** - Little demographical information collected - Majority of individuals who had died had cancer; not necessarily representative of assisted deaths in other circumstances - Unclear analysis framework
Exploring the experience of supporting a loved one through a medically assisted death in Canada. Holmes, Wiebe, Shaw, Nuhn, Just & Kelly (2018)	To explore the experience of family and close friends of patients seeking MAiD in Canada.	18 support people for patients seeking (or who had) a MAiD death.	Semi-structured interviews (telephone, email, video-conferencing)	Thematic content analysis	Themes identified in relation to the journey of supporting a loved one through MAiD were; initial reactions to loved ones sharing their wishes around MAiD, and how perspectives changed on this during the process; the experience of helping with preparations for MAiD; the day of the death itself and subsequent reflections and	**Strengths:** - Qualitative research design is appropriate to explore experiences of sample on under researched topic - Clear justification for study design and methods used - Included friends in sample of 'family members' - Multiple coders used at analysis stage to improve triangulation **Weaknesses:**

Canada					comparing MAiD to a 'natural' death.	- Little detail about analysis process - Unclear whether relationship between researchers and participants has been considered, particularly as those interviewing were physicians (unclear if participants are aware of this) - Unclear if ethical considerations were addressed
Improving the Medical Assistance in Dying (MAID) process: A qualitative study of family caregiver perspectives. Hales, Bean, Isenberg-Grzeda, Ford & Selby (2019) Canada	To understand family caregiver perspectives on MAiD at a specific centre in Canada and consider opportunities for service improvement.	11 family caregivers of people who had a MAiD at this centre.	Structured survey, focus group and unstructured e-mail/phone conversations.	Thematic analysis	Opportunities for improvement were identified in relation to operational and experiential aspects of the MAID process. Themes from the operational aspects included; process clarity, scheduling challenges and the 10 day period of reflection. Themes from the experiential aspects included clinical judgment / objection, secrecy / privacy and bereavement support.	**Strengths:** - Clear recruitment strategy - Participants could choose how they wanted to participate in the study - Clear sense of how results of study will be used in improving service provision **Weaknesses:** - Researcher does not own positionality or discuss impact of potential biases on research - Recruited from one MAiD centre; possible limited generalisability - Unclear analysis framework - Quality improvement focus may have impacted which results were shared / privileged
The relational landscape of bereavement after anticipated death: An interpretive model. Laperle, Achille & Ummel (2022) Canada	To build on existing bereavement literature and explore bereavement in the context of anticipated grief, in order to develop an interpretive model of grief.	16 family members bereaved by euthanasia or 'natural' death.	Semi-structured interviews (combination of face-to-face and online)	Interpretive Description	A relational landscape of bereavement model was developed. This incorporates the different people in bereavement environments and the variety of interactions between them. This can inform what the bereavement 'landscape' looks like surrounding a death and how this might affect bereavement.	**Strengths:** - Qualitative research design is appropriate to explore experiences of bereavement - Clear aims, and clearly described how aims were met - Contributes a new model of bereavement to the literature - Clear purposeful recruitment strategy for needs of research **Weaknesses:** - Unclear analysis framework - Although ethical issues and relationship between researcher and participants considered it is not clear *how* these were addressed
A Race to the End: Family Caregivers' Experience of Medical Assistance in Dying (MAiD) - a Qualitative Study.	To better understand family caregivers' experiences of MAiD in Canada.	22 caregivers of patients who had requested MAiD.	Semi-structured interviews (face-to-face or telephone)	Grounded theory	The 'race to the end' analogy was developed to describe caregivers' experiences of MAiD. Caregivers were categorised as either 'co-runners' (supporting and	**Strengths:** - Qualitative research design is appropriate to explore experiences of sample on under researched topic - Range of demographical information collected

Thangarasa, Hales, Tong, An, Selby, Isenberg-Grzeda, Li, Rodin, Bean, Bell & Nissim (2022) Canada					advocating for the patient) or ‘on-lookers’ (taking a more passive role) ahead of ‘setting up for the finish line’ (the death) for their loved one. These roles were informed by their relationship with the person using MAiD and their own feelings towards MAiD, and are identified to bring different sources of distress to caregivers.	- Contributes a new model of caregiver experiences of the MAiD process using an accessible metaphor - Consideration given to psychological safety in interviews **Weaknesses:** - Unclear recruitment process - Unclear if ethical approval was received - Unclear if the authors considered the relationship between the author(s) and participants - Implications for study being funded by the Canadian Cancer Society not discussed or acknowledged.
Care Considerations in a Patient- and Family-Centered Medical Assistance in Dying Program. Brown, Goodridge, Harrison, Kemp, Thorpe & Weiler (2022) Canada	To evaluate opportunities to enhance patient and family-centred care in a specific MAiD program in Canada.	5 patients who requested an assessment for MAiD, 11 family members, and 14 healthcare providers.	Semi-structured interviews	Thematic analysis	Stakeholders’ experiences of MAiD can be grouped into four different themes for care consideration on the MAiD program; emotional, physical, relational and spiritual, alongside a number of subthemes. These can inform development of clinical practice and policy at this MAiD program.	**Strengths:** - Qualitative research design is appropriate to explore experiences and ensure these stakeholder views on the care offered at this program are heard - Range of demographical information collected - Gathered information from multiple stakeholder perspectives - Clear sense of how the information gathered would be used in clinical practice **Weaknesses:** - Unclear recruitment process - Unclear analysis framework - No ethnic diversity in sample
Experiences of grief-bereavement after a medically assisted death in Canada: Bringing death to life. Beuthin, Bruce, Thompson, Andersen & Lundy (2022) Canada	To understand the experiences of bereaved people after the assisted death of a loved one.	9 family members or friends of people who had MAiD.	Semi-structured interviews (face-to-face or telephone)	Interpretive description	MAiD is described as a way of “bringing death to life” with three sub-themes of influences of grief-bereavement; knowing when the death would occur, role taken in planning the death / the process and MAiD being seen as a ceremony rather than a medical procedure.	**Strengths:** - Qualitative research design is appropriate to explore experiences of grief-bereavement - Use of ‘short story’ and ‘found poetry’ techniques to highlight participants’ experiences - Recruitment from the community; not just clinical sample - Consulted patient advisor during analysis, increasing trustworthiness of findings

Weaknesses:

- Lacking detail about recruitment process
- Lack of ethnic and gender diversity of sample
- Unclear analysis framework
- Researcher does not own positionality with the research
- Unclear if ethical considerations were addressed

1.7.4 Quality assessment

Qualitative research is increasingly being used, alongside quantitative research, to inform healthcare policy and practice and therefore it is essential that the quality of this research can be demonstrated (Crowe et al., 2017). As such, quality assessment tools can be utilised as a way to systemically assess research quality (Long et al., 2020).

For this SLR, the Critical Appraisal Skills Programme (CASP) tool was chosen to assess the quality of chosen studies (CASP, 2018). This tool comprises ten questions aimed at systematically assessing the rigour, credibility and relevance of qualitative studies as markers of research quality. It was selected for a number of reasons. Firstly, it is a tool commonly used in qualitative health research and therefore appropriate to this topic. Furthermore, its endorsement by the Cochrane Qualitative and Implementation Methods Group suggests its effectiveness. It has also been recommended for use by novice researchers, suggesting its accessibility (Long et al., 2020). Finally, it fits with the epistemological position taken for this research in privileging research that is systematic and trustworthy (demonstrated by methods such as triangulation and/or clear audit trails of how the research was conducted; Finlay, 2006).

Each paper was assessed against the ten criteria. If the researcher wasn't initially sure of which mark to assign ('Yes' = criteria met, 'No' = criteria not met, 'Can't tell' = unclear whether criteria has been met), notes were made and reviewed before the final mark was decided. The final quality ratings given for each paper are shown in Table 4.

Table 4 – Results of critical appraisal of study quality

		CASP Appraisal Checklist									
		1	2	3	4	5	6	7	8	9	10
Paper, journal, author(s), date of publication	Author information	Was there a clear statement of the aims of the research?	Is a qualitative method appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between the researcher and participants been adequately considered?	Have ethical issues been taken into consideration? [3]	Was the data analysis sufficiently rigorous? [4]	Is there a clear statement of findings?	How valuable is the research?
Title: *Exploring the experiences of bereaved families involved in assisted suicide in Southern Switzerland: a qualitative study.* **Journal:** British Medical Journal (BMJ)	**Author(s) / date of publication:** Gamondi et al. (2015) **Profession / affiliations of first author:** Affiliated with the Palliative Care Department, Oncology Institute of Southern Switzerland and the Palliative Care Service, Centre Hospitalier Universitaire Vaudois, Lausanne, Switzerland	Yes	Yes	Yes	Yes (although most is detailed elsewhere)	Yes	Can't tell	Yes	Yes	Yes	Details emotion burden experienced by family members involved in an assisted suicide. Challenges the notion that legalised assisted dying promotes open dialogue about it. Focuses on how the information collected can be used to inform policy.

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[3] Ultimately if a study acknowledged that it had received ethical approval, ethical issues were felt to have been considered.

[4] Data analysis was considered 'rigorous' through assessment of the 'hints' in the CASP checklist, and level of detail provided in the paper; despite identified concerns (below) about some deviation from traditional frameworks.

Title: *Family Caregivers' Reflections on Experiences of Assisted Suicide in Switzerland: A Qualitative Interview Study.* **Journal:** Journal of Pain and Symptom Management	**Author(s) / date of publication:** Gamondi, et al. (2018) **Profession / affiliations of first author:** Affiliated with the Palliative Care Department, Oncology Institute of Southern Switzerland and the Palliative Care Service, Centre Hospitalier Universitaire Vaudois, Lausanne, Switzerland	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Details Swiss family members' experiences of assisted suicide, and the integral role they play in the process. Offers clinical recommendations for supporting patients and families considering an assisted suicide.
Title: *Swiss Families' Experiences of Interactions with Providers during Assisted Suicide: A Secondary Data Analysis of an Interview Study.* **Journal:** Journal of Palliative Medicine	**Author(s) / date of publication:** Gamondi et al. (2020) **Profession / affiliations of first author:** Affiliated with the Palliative Care Department, Oncology Institute of Southern Switzerland and the Palliative Care Service, Centre Hospitalier Universitaire Vaudois,	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Adds to the literature on this topic by specifically focusing on how families view interactions with providers (professionals / right to die organisations) during the assisted suicide period.

	Lausanne, Switzerland										
Title: *Bereavement and the Oregon Death with Dignity Act: How does assisted death impact grief?* **Journal:** Death Studies	**Author(s) / date of publication:** Srinivasan (2019) **Profession / affiliations of first author:** Associate Professor, Department of Psychology, University of Wisconsin	No	Yes	Yes	Yes	Can't tell	Can't tell	Can't tell	Yes	Yes	Contributes to the evidence base around bereavement experiences following an assisted death.
Title: *"I lost so much more than my partner" – Bereaved partners' grief experiences following suicide or physician-assisted dying in case of a mental disorder* **Journal:** BMC Psychiatry	**Author(s) / date of publication:** Snijdewind (2022) **Profession / affiliations of first author:** Assistant Professor in Aging and Later Life; Personalised Medicine & Ethics and Law & Medical Humanities. Amsterdam AMC.	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Offers insight into the experiences of partners bereaved by assisted death or suicide and the similarities and differences between the two. Similarly it offers an opportunity to consider these in the context of mental rather than physical health struggles being the reason for death.
Title: *Caregivers' Experiences With Medical Aid-In-Dying in Vermont: A Qualitative Study.*	**Author(s) / date of publication:** Buchbinder et al. (2018) **Profession / affiliations of first author:** Professor of Social Medicine	Yes	Yes	Yes	Can't tell (detailed elsewhere)	Yes	Can't tell	Yes	Yes	Yes	Offers insight into different caregivers experiences of their loved one using AID in Vermont. Supports findings from Switzerland highlighting the instrumental role that family

Journal: Journal of Pain and Symptom Management	and Adjunct Professor of Anthropology at UNC – Chapel Hill / Core faculty in the UNC Centre for Bioethics.										members play during this period and offers suggestions for clinical practice around involvement of all relevant close people to the patient; not just biological family members.
Title: *Exploring the experience of supporting a loved one through a medically assisted death in Canada.* **Journal:** Canadian Family Physician	**Author(s) / date of publication:** Holmes et al. (2018) **Profession / affiliations of first author:** Internal medicine resident at the University of British Columbia.	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Can’t tell	Yes	Provides insight into the experiences of ‘support people’, who have supported a loved one through the MAiD process in Canada, after it had been legal in the country for 5 years.
Title: *Improving the Medical Assistance in Dying (MAID) process: A qualitative study of family caregiver perspectives.* **Journal:** Palliative & Supportive Care	**Author(s) / date of publication** Hales et al. (2019) **Profession / affiliations of first author:** Director of Quality & Patient Safety at Sunnybrook Health Sciences Centre, Toronto	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Offers understanding of family caregivers perspectives on the quality of the MAiD process offered, rather than focus being on experience of being involved.
Title: *The relational landscape of bereavement after anticipated*	**Author(s) / date of publication:** Laperle et al. (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Presents a new model of bereavement following an anticipated death, adding to current

death: An interpretive model. **Journal:** Death Studies	**Profession / affiliations of first author:** Clinical Psychologist in the Addiction Psychiatry Program at the University of Montreal and research / clinical work undertaken at the Maison du deuil.										literature on the topic.
Title: *A Race to the End: Family Caregivers' Experience of Medical Assistance in Dying (MAiD) - a Qualitative Study.* **Journal:** Journal of General Internal Medicine	**Author(s) / date of publication:** Thangarasa et al. (2022) **Profession / affiliations of first author:** Roles unclear. Affiliated with the Department of Supportive Care at the University Health Network, Toronto and the Department of Psychiatry at the University of Toronto.	Yes	Yes	Yes	Can't tell	Can't tell	Can't tell	Yes	Yes	Yes	Contributes a new model of caregiver experiences of the MAiD process using an accessible metaphor, and considers how predicting distress at different points in the process can inform clinical interventions for supporting caregivers. Considers this is relation to evolving policy.
Title: *Care Considerations in a Patient- and Family-Centered Medical Assistance in Dying Program.*	**Author(s) / date of publication:** Brown et al. (2022) **Profession / affiliations of first author:** Associate Dean (Faculty Affairs), Faculty of	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Yes	Yes	Provides insight into different stakeholders' experiences of this MAiD program and considers how these understandings can inform different aspects of clinical practice. Highlights

Journal: Journal of Palliative Care	Nursing, University of Regina.										the need for these perspectives to be included in policy development.
Title: *Experiences of grief-bereavement after a medically assisted death in Canada: Bringing death to life.* **Journal:** Death Studies	**Author(s) / date of publication:** Beuthin et al. (2022) **Profession / affiliations of first author:** Care Coordinator, Medical Assistance in Dying and Nurse Researcher, End of Life Care, Vancouver Island Health Authority, Canada	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Provides an understanding of bereavement of individuals following a loved one using MAiD, and the ways in which it differs to bereavement following a ‘natural’ death. This supports other literature on this topic. Highlights the importance of rituals and meaning making, and how family members may be supported in this process.

1.7.5 Quality evaluation of the literature

All studies received a moderate-high quality rating on this tool. This suggests that their findings can be viewed as credible and trustworthy and as offering meaningful contributions to the literature. All expect one (Srinivasan et al., 2019) identified clear aims, which aided the assessment of other decisions made within the research process, however none detailed specific research questions.

A qualitative methodology (or mixed methodology; Snijdewind, 2022) was felt appropriate to the research objectives for all studies, but the level of clarity about different aspects of the methods used was mixed. For example; some detailed clear recruitment strategies (Hales et al., 2019; Snijdewind, 2022; Srinivasan et al., 2019), whereas others offered an explanation of the recruitment process but lacked sufficient detail (Beuthin et al., 2022; Gamondi et al., 2018; 2020; Holmes et al., 2018; Laperle et al., 2022). In two studies, the recruitment strategy was not clear (Brown et al., 2022; Thangaresa et al., 2022) and others also did not detail this process; stating it was described elsewhere (Buchbinder et al., 2018; Gamondi et al., 2015). However, Gamondi and colleagues (2015) did provide useful information around why family members declined to take part in their research (information often not disclosed) which was useful in informing recruitment for future research.

All studies shared demographical information collected about participants. Some gathered a wide range of useful information (e.g., Brown et al., 2022; Snijdewind, 2022; Thangaresa et al., 2022), whereas others collected less information (e.g., Buchbinder et al., 2018). It was noted that only three studies appeared to collect information about ethnicity (Brown et al., 2022; Srinivasan et al., 2019; Thangaresa et al., 2022), although Beuthin and colleagues (2022) spoke to generalisability issues based on ethnicity and age in their discussion, suggesting this information was gathered, but not reported. Furthermore, only two studies collected information about religious beliefs (Srinivasan et al., 2019; Thangaresa et al., 2022). The majority of authors acknowledged limitations to their study based on the participant demographics they collected and/or location of study (e.g. recruitment from one clinic) in their discussion. This transparency was felt important in considering the generalisability of findings.

When reviewing analysis methods, some studies were clear on the method used (e.g., Gamondi et al., 2018; 2020; Snijdewind, 2022; Srinivasan et al., 2019; Thangaresa et al., 2022). Others, however, were less transparent about this. For example; Laperle and colleagues (2022) describe that they *“referred mainly to Thorne’s (2016) Interpretative Description…”,* Beuthin and colleagues (2022) describe *“drawing on interpretative description”* and Buchbinder and colleagues (2018) describe using an *“inductive iterative approach guided by the tenets of grounded theory”*. Gamondi and colleagues (2015) spoke to using the *“principles”* of grounded theory, and others appeared to use a combination of approaches (e.g., Brown et al., 2022; Hales et al., 2019). It was not always clear how these methods deviated from original analysis frameworks, possibly impacting the integrity of findings. Two studies (Buchbinder et al., 2018; Gamondi et al., 2020) conducted secondary analyses. This was viewed positively, given the toll on participants in taking part in research, and therefore the benefits of making use of data already available.

Some studies described ways they had addressed ethical considerations in the research process, such as considering the comfort of participants in interviews (e.g., Gamondi et al., 2018; Thangaresa et al., 2022) and participants being able to choose how they wanted to participate in the study (e.g., Hales et al., 2019). For others, however, it was less clear if/how ethical considerations were addressed (e.g., Beuthin et al., 2022; Gamondi et al., 2015; 2020; Holmes et al., 2018; Laperle et al., 2022), but the receipt of ethical approval in these studies mitigated concerns. However, the study by Srinivasan (2019) did not state whether ethical approval was received. This raises concerns about the ethical integrity of this research.

Some studies appeared to have considered the influence of researcher positionality (e.g. Buchbinder et al., 2018; Gamondi et al., 2015; 2018; 2020; Laperle et al., 2022), although it was often not clear if/how this was addressed. One study consulted with a patient advisor during the analysis process (Beuthin et al., 2022), and others involved multiple researchers at this stage to improve inter-rater reliability (e.g., Buchbinder et al., 2018; Gamondi et al., 2020; Snijdewind, 2022). Whilst most studies acknowledged funding and/or declaration of interests, some did not identify any conflicts of interest (e.g., Brown et al., 2022; Hales et al., 2019; Holmes et al., 2018; Srinivasan, 2019). It was also noted that the majority of studies were published in medical journals, with an assumed medical audience. This is likely to have impacted the foci of these papers and may suggest why these 'reflexive' elements around positionality and bias are commonly missing and/or lacking detail. This is perhaps because this audience may consist of those making the final decision about assisted deaths and therefore information presented as fact might be desirable to support that binary decision. Overall, across studies, it was felt that it would have been helpful to have further clarity on author positionality/possible biases to be able to contextualise results.

Finally, when reflecting on this quality appraisal process, I have witnessed the benefits of these quality assessment tools in assessing research quality but also questioned whether these assessments may privilege more western / Eurocentric approaches to conducting research. I have wondered whether studies scoring lower on these tools are always less valuable or 'trustworthy', or whether, perhaps in some cases, they may have just used less traditional approaches that don't fit the tools' criteria. This suggests a possible bias in the type of research deemed of high enough quality to inform healthcare provision. I have noted, however, that all the studies included in this SLR were conducted in western countries, likely taking these more 'traditional' approaches to conducting research. I plan to consider these reflections further as I go forward in my research practice.

1.7.6 Synthesis of findings

Thematic analysis (TA) using a theoretical approach (guided by a question; Braun & Clarke, 2006) was used to synthesise the data collected from the SLR. TA was chosen as it is useful in identifying patterns in data, and its flexible approach fits within a range of theoretical frameworks and underpinning epistemologies. It was noted that it offers the opportunity to gather understandings of reality whilst simultaneously unpicking the associated meaning (Braun & Clarke, 2006), fitting with the critical realist epistemological position taken for this research. It was hoped that TA would be a useful way of analysing and collating views of family members within the available literature, ahead of using IPA in this study to understand the perspectives of family members in the UK in more depth.

The TA followed the steps outlined by Braun and Clarke (2006);

1. Familiarising yourself with the data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

The included studies were read multiple times for familiarisation before reviewing the specific data that related to the SLR question. Initial codes were generated from this data that were then grouped into themes and subthemes, reviewed and then refined, before producing the final themes.

TA found four themes, each with associated subthemes (see Table 5).

Table 5 – Themes generated from TA

Theme	Subtheme
1. Agency over end of life	1. Preventing unbearable suffering
	2. The “gift” of choice
	3. Death with dignity
2. Ability to say goodbye	1. Preparing for the end
	2. Time together / being with
	3. Ending rituals
3. Impact on loved ones	1. Challenging belief systems
	2. Secrecy and stigma
	3. Emotional burden
4. Alternative options	1. Assisted dying versus suicide
	2. Assisted dying versus palliative care

Theme 1: Agency over end of life

The literature identified various ways that family members view assisted dying as offering an individual agency over the end of their life, through preventing unbearable suffering, offering the *“gift”* of choice, and a death with dignity.

Subtheme 1: Preventing unbearable suffering

The subtheme ‘Preventing unbearable suffering’ was present in five papers (Gamondi et al., 2018; Hales et al., 2019; Holmes et al., 2018; Snijdewind, 2022; Srinivasan, 2019).

References were made to the physical and psychological suffering that can come from living with medical diagnoses, and assisted dying being viewed as the only way to end this unbearable suffering;

“I had to control the situation, I had only one aim: to kill my wife. It is horrible but…but I believe that in such a situation, there are no other means, there are no other aims…”. (Gamondi et al., 2018, p. 1089)

It was also recognised that the nature of the death being planned via the ‘Death with Dignity Act’ (DWDA, the law passed in Oregon that permits assisted dying in certain contexts; Oregon Health Authority, n.d.) can be comforting for the individual, despite them experiencing ongoing unbearable suffering;

“[The DWDA] really helped to avoid quite a lot of unnecessary pain, both physical and emotional, as he would’ve been…anxious and fighting death, but anxious about wanting it to

come and take him and not knowing when that would happen and being in pain and not being able to…to end it—just keeping the ability to end his pain. Words can't describe how…compassionate that is, really, and how comforting to him and to us. So, it helped enormously with…what's a very difficult situation. It helped make it better. It really did". (Srinivasan, 2019, p. 650)

Others suggested that assisted dying is a way of preventing pre-empted future unbearable suffering associated with old age;

"Assisted death is a way to de-anguish the world…there is a great anguish in facing old age and death". (Gamondi et al., 2018, p. 1089)

And the impacts of expected deterioration in health on quality of life;

"It avoided whatever prolonged misery [there] might have been. I think it worked absolutely perfect for us. She clearly was failing. She was failing so fast, and that wasn't the life that either one of us wanted to live". (Srinivasan, 2019, p. 650)

These quotes speak to the psychological suffering experienced through witnessing one's own deterioration, alongside perhaps connecting to negative societal beliefs about old age and dying.

Subtheme 2: The "gift" of choice

The subtheme 'the *"gift"* of choice' was present in four papers (Holmes et al., 2018; Laperle et al., 2022; Srinivasan, 2019; Thangarasa et al., 2022). Assisted dying was described as a *"gift"* to those who sought it;

"It was a great gift that she didn't die in the way so many other people I know die, so tragically and so painfully". (Srinivasan, 2019, p. 650)

This was connected with the benefits of choice and agency;

"I think it was a gift that he could make that choice. And I know a lot of people just get the stuff and don't ever do it, and I'm all for that, too, 'cause…it puts you in a position of choice. Position of a little bit of power over, you know…And I think that, like I said, it was a very positive thing for us". (Srinivasan, 2019, p. 650)

Particularly at a time where agency has been lost;

"I think that for my mother it was the best outcome in very difficult circumstances because she lost a lot of agency in her last three, four months. She's always been in charge of her own things and she's very proud of that. And then with the illness, I felt like she lost a lot of control of her life, but this was something that she decided and requested…it gave her some agency and so I think that it was really the best outcome for her". (Thangarasa et al., 2022, p. 811)

And the benefits this has for the individual and their family;

"But I still think…the fact that somebody has the opportunity to have control when they basically had no control is probably the most important thing, for the family, for the individual". (Srinivasan, 2019, p. 650)

This theme speaks to family members' witnessing a lack of agency that living with a medical condition can bring (e.g., lack of independence, not feeling in control of illness trajectory), and as such viewing the option for an assisted death as a way of offering some agency in these situations.

Subtheme 3: Death with dignity

The subtheme 'Death with dignity' was present in two papers (Brown et al., 2022; Holmes et al., 2018). The assisted death of a family member was generally identified using terms related with dignity such as *"joyful and peaceful"* (Buchbinder et al., 2018, p. 940), *"serene"* (Holmes et al., 2018, p. e391) and *"graceful"* (Holmes et al., 2018, p. e391)*;*

"sad [and] though it was and will remain so for some while yet, it was peaceful, and graceful". (Holmes et al., 2018, p. e391)

However, one participant in a study appeared to be expecting that dignified experience, but in reality the assisted death of their family member did not meet these expectations;

"What was horrible—horrible—was to hear him scream and cry out every single bump…it could have been so beautiful and peaceful if she [the physician] could have just come into the room there. It could have been that simple and that beautiful for him, and for us too". (Holmes et al., 2018, p. e391)

This suggests that generally the views presented by organisations that are pro-assisted dying (e.g., that assisted dying offers a dignified and peaceful death), fits with family members' experiences of being part of an assisted death, but that this may not always be the case.

Theme 2: Ability to say goodbye

The literature identified that family members view assisted dying positively due to it having offered them the ability to say goodbye to their loved one. This was associated with benefits associated with preparing for the end, time together/being with, and being able to undertake ending rituals together.

Subtheme 1: Preparing for the end

The subtheme 'Preparing for the end' was present in four papers (Beuthin et al., 2022; Holmes et al., 2018; Srinivasan, 2019; Thangarasa et al., 2022). The literature acknowledged family members seeing benefits of assisted dying in allowing the family to prepare for the death together;

"[Agreement] eased it [grief] a lot. 'Cause we're all in the same boat. We're all on the same track. We're all in the same mind. It was almost like one person's decision. You can't get better than that, I don't think". (Srinivasan, 2019, p. 650)

This was acknowledged as being valuable for the individual having the assisted death;

"I arrived in Vancouver 5 days prior to the day of her death. We had told everyone who was close…My brother who hasn't had a good conversation with her in 10 years…they had 4 or 5 good conversations…it was almost like a perfect week for her, when everyone would call her and share stories for her…her grandchildren would call her every single day, and how many grandparents get that"? (Holmes et al., 2018, p. e391)

But also comforting for family members; and enabling them to plan their own support;

"When you know in advance that…somebody's going to die, you have an amount of preparation that is…very comforting. With this one you've got a very specific when, and so you can have people come in and…you can be surrounded by people who are comforting to you. I loved the idea that I could have the house full of people to laugh with, to cry with, or whatever". (Srinivasan, 2019, p. 649)

This supports the theme around assisted dying offering the *"gift"* of choice. That theme suggested that family members can see the benefits of the individual having the choice to end their life and unbearable suffering. This theme suggests that this control makes it possible to choose how the end of life will actually look in practice.

Subtheme 2: Time together/being with

The subtheme 'Time together/being with' was present in two papers (Gamondi et al., 2018; Holmes et al., 2018). Whilst planning the assisted death makes time together possible, family members viewed the time together itself as invaluable and offering closure;

"For us to spend all of that time before was such a privilege…She loved all of those talks on the phone. She probably spent 6 hours a day on the phone for those 7 days before her

death…so emotionally I think there is a real sense of closure...". (Holmes et al., 2018, p. e392)

It is also suggested that the experience of dying surrounded by loved ones is precious;

"Having lived through one, I can't believe how wonderful, if I can put it in those terms, passing away can be. My wife was very comfortable, very serene, surrounded by friends, family. The time was her choosing, and that was something that was extremely important and very, very meaningful". (Holmes et al., 2018, p. e391)

Subtheme 3: Ending rituals

The subtheme 'Ending rituals' was present in three papers (Buchbinder et al., 2018; Gamondi et al., 2018; Holmes et al., 2018). Family members appeared to view the opportunity for ending rituals as a positive part of assisted dying. Whilst, for one family member being there with their family member was more important than specific ending rituals;

"I like rituals…it wasn't necessary…I didn't get a sense that she wanted anything else, other than to proceed to what was her goal…you don't need the stage management when your major goal is to have a peaceful death…if you can just be there with them so you're as close to them as possible, I think that's what's critical". (Holmes et al., 2018, p. e391)

Others noted the benefits of being able to engage in rituals together as a family to mark the end;

"They were all in a circle with a candle lit and they were emptying the capsules together and they were being playful, and just the most beautiful energy, loving and making jokes and everything, and they prepared it". (Buchbinder et al., 2018, p. 940)

"We shared with him the things we loved and were grateful for and the funny things. It was so beautiful…we said our love and our goodbyes…I am always one for ceremonies; I think it is so important". (Holmes et al., 2018, p. e391)

This recognises that family members view ending rituals associated with death as important, and raises a question of how these may be impacted by the illegal status of assisted dying in the UK.

Theme 3: Impact on loved ones

Despite family members generally appearing to view assisted dying in a positive light, it was noted that it doesn't come without impacts on loved ones. These include: assisted dying challenging family members' belief systems, the felt need for secrecy due to ongoing stigma around assisted dying and the emotional burden that assisted dying can bring to family members.

Subtheme 1: Challenging belief systems

The subtheme ‘Challenging belief systems’ was present in six papers (Beuthin et al., 2022; Brown et al., 2022; Gamondi et al., 2015; 2018; Holmes et al., 2018; Srinivasan, 2019). Many family members shared initial apprehension with the idea of their family member having an assisted death. For some, this was due to religious beliefs and attempting to work out where assisted dying fitted with these;

> *‘‘We are Catholic, dad wasn’t you know. So, a little bit of that belief came into play, but toward the end we were all right with him. We knew what he wanted and we respected that’’.* (Brown et al., 2022, p. 347)

> *“I was in a little bit of turmoil…I knew what I felt in my heart, but there was still turmoil and the thought that maybe, being a Christian, you shouldn’t be supporting this. But…I thought, “Whatever K.’s thoughts are with God, that’s between K. and God—don’t get into the middle of that.” There was an undercurrent of conflict…I don’t know what God thinks about assisted suicide, but I think He understands why K. did what he did. I went and made an appointment with one of the associate pastors in our church. They said, “You’re right on. God’s a loving God and don’t worry about it.” So that was kind of reassuring to me”.* (Srinivasan, 2019, p. 651)

Whereas for others, initial complicated views on assisted dying were connected with the dissonance between professional caregiving beliefs and personal beliefs around ending unbearable suffering;

> *“…I’m a caregiver—that’s what I do both emotionally and professionally—and so it was harder to think that you’re just going to die, and you’re going to die before you really need…You could live longer. You don’t have to choose it now. You could choose another day, choose another month. So there were some emotional…kind of resolving that it was B.’s choice”.* (Srinivasan, 2019, p. 651)

Others connected with the shock of hearing about the desire for an assisted death initially, due to the finite nature of the decision, but noted that their views on assisted dying changed after witnessing their loved one have an assisted death;

> *“I was first saddened and somewhat shocked at her decision. Likewise, I felt it somewhat drastic…knowing that it was not only a conscious decision on her part, but also one that she would not have made lightly had other alternatives been available. In retrospect, I now think it was a very brave and courageous decision on her part”.* (Holmes et al., 2018, p. e390)

This suggests that family members' initial views on assisted dying are impacted by a range of contextual factors, but that being part of the assisted dying process appeared to generally resolve any initial reservations and leave family members viewing assisted dying positively.

Subtheme 2: Secrecy and stigma

The subtheme 'Secrecy and stigma' was present in five papers (Brown et al., 2022; Gamondi et al., 2015; 2020; Hales et al., 2019; Srinivasan, 2019).

References were made to assisted dying being a stigmatised way to die;

"It's kind of like the first people getting abortions–[it's legal] but there's still stigma. And: "What did you do and what processes did you go through?" And [the implication that] maybe you forced somebody". (Srinivasan, 2019, p. 52)

Which was seen as *"absurd";* suggesting that this should no longer be the case;

"I find absurd that in 2009 we have still to cover this thing (assisted suicide)". (Gamondi et al., 2015, p. 150)

This was identified as leading to a need for secrecy around the mode of death, despite family members supporting assisted dying themselves;

''My problem right now is I don't share with people. I share very limited with people that mom's passing was done through MAID. And my, it's not because I don't 100% believe it". (Brown et al., 2022, p. 347)

Family members appeared to view assisted dying as a mode of death not generally acceptable to others. This perceived stigma and the need for secrecy was identified despite the studies being conducted in countries where assisted dying is legal. This raises questions about how family members might view this, or the possible extent of associated stigma, in countries where assisted dying is not legal, such as the UK.

Subtheme 3: Emotional burden

The subtheme 'Emotional burden' was present in four papers (Gamondi et al., 2015; 2018; Srinivasan, 2019; Thangarasa et al., 2022). Some family members viewed assisted dying as bringing emotional burden to others surrounding the individual;

"He [the patient] took us on difficult and sometimes impossible roads". (Gamondi et al., 2018, p. 1089)

Often due to wondering whether other options could still be explored;

"Control is very important to him. So, I think he had kind of processed it, and said he wanted to go ahead with it, and he wanted me to support it. And I had a hard time supporting it because I still said, 'maybe it's too early, maybe there's hope because you responded to the radiation well, and this radiation sickness could pass". (Thangarasa et al., 2022, p. 811)

And moral dilemmas around whether or not it was the right decision;

"But your conscience works and tells you: "well…is it right? Is it not right? He wanted…yes…but…" Perhaps I could have influenced him, being the daughter. You ask yourself a thousand of questions". (Gamondi et al., 2015, p. 149)

For one participant, this led the family member to wishing that their loved one would die naturally while waiting for the assisted death to relieve them of this burden;

"In the last days every morning I was hoping to find him dead…especially when you start on that road (assisted suicide), you tell yourself "maybe he can die peacefully before". (Gamondi et al., 2015, p. 149)

This subtheme highlights the complexities for family members in navigating an assisted death of a loved one, suggestive of the need to consider how family members can be supported during this period.

Theme 4: Alternative options

Within the literature, views around assisted dying were also discussed in relation to possible alternatives; (non-assisted) suicide and palliative care.

Subtheme 1: Assisted dying and suicide

The subtheme 'Assisted dying and suicide' was present in three papers (Gamondi et al., 2015; 2018; Thangarasa et al., 2022). For some, assisted dying was seen as the preferred option to 'traditional' suicide (without assistance);

"At that point I said to myself: better like this (assisted suicide) at the end, because if he would have done differently (classical suicide) it could have been worst. And at least he is cared for…it is a bad thing, but I thought: it is better like this…it is a painless thing, safe, without worst consequences". (Gamondi et al., 2015, p. 149)

For others, their views on assisted dying were equated to how they feel about suicide and the associated stigma;

"Part of what underlies my discomfort is that, I think that suicide in any form is a bit of a coward's way out. It solves a lot of problems for the person who is undergoing it. It leaves a

whole ton of problems for the people behind…in my mind, it's the ultimate selfish act". (Thangarasa et al., 2022, p. 813)

Others extended this to consider how they viewed people that supported the decision;

"The violence is there too [in assisted suicide]…a different violence [comparing with natural death or classic suicide]. It is there, but it is spread over the people that follow the patient in their decision". (Gamondi et al., 2018, p. 1089)

This suggests that not all family members' views on assisted dying are positive, and stigma around this mode of death is still prevalent, even when family members haven't experienced it. It also proposes that there is implication in this stigma for everyone aware of the assisted death in both its meaning and impact for those connected to the person that died.

Subtheme 2: Assisted dying versus palliative care

The subtheme 'Assisted dying and palliative care' was present in one paper (Gamondi et al., 2020). This study shared perspectives on where assisted dying might fit in relation to palliative care. All contributors to this subtheme agreed that improvements in palliative care would not remove the need for assisted dying as an option;

"We cannot say that we need to develop palliative care as an alternative to Exit (a right to die association); for me it's a mistake to think that by developing palliative care, people will use Exit less. It's just two different things". (Gamondi et al., 2020, p. 12)

It was identified that;

"…palliative care does not solve the existential question of life and end of life as it is. Palliative care offers…an alternative to a medicine focused in maintaining life...it is an accompaniment to death, in my perception…in best possible conditions, but it (Palliative care) cannot take the place". (Gamondi et al., 2020, p. 12)

This suggests that family members view both assisted dying and palliative care as having a valuable position in end of life care.

1.7.7 SLR conclusions and clinical implications

This SLR identified that family members play a significant role in the preparations before and on the day of an assisted death, which can be beneficial for both the individual choosing to die and the family left behind. Assisted dying is viewed by some as offering a valuable option to those experiencing unbearable suffering, or pre-empting future unbearable suffering, but family members can face challenges coming to terms with the choice their loved one has made. It appears that contextual factors (e.g., societal views around suicide, family beliefs systems) may influence family members' views, with some still disapproving of this mode of death, whereas others appear to view assisted dying more positively after having seen a loved one die in this way.

More generally, some studies advocated for clinicians to be more proactive in information sharing with family members (e.g., Gamondi et al., 2020), suggesting the benefits of family involvement to both the individual seeking the assisted death and their family members (Buchbinder et al., 2018). Whilst others noted the importance of better understanding the impact on family members, and possible sources of distress, in order to understand the impact on grief and consider how they can best be supported (Thangarasa et al., 2022). Overall, the literature suggests the need to better understand family members perspectives, and to ensure that these are considered when developing guidelines and policies on this topic (e.g., Hales et al., 2019).

1.7.8 Gaps identified in the literature

This SLR highlighted gaps in the literature. Firstly, despite the focus of the SLR being the *views* of family members, the literature available appeared to focus on the *experiences* of family members (who had been part of the preparations and/or procedure for an assisted death with a loved one and in countries where this is permitted), or considered how this type of death might impact bereavement. Some information, although limited, was gathered about their perspectives on assisted dying more generally, but overall access to family members' views on this topic is limited. This limited my ability to offer an in-depth insight of family members views on assisted dying across the world, as per my SLR question. It is also important to note that 11 records that may have been relevant to this SLR were unable to be accessed. It is possible that these may have offered meaningful contributions to this SLR and could have provided valuable information towards further answering my SLR question.

Nevertheless, this SLR offered valuable insights into these views on assisted dying, as well as useful information to inform the development of this study (e.g., in informing the development of this study's research questions). The limited research available also demonstrates the need for further research into family members' perspectives on this topic.

Finally, all papers included in the SLR were from countries where assisted dying was legal at the time of study publication, with a noticeable absence of research from countries where assisted dying is not legal, including no studies based in the UK. This offers a unique opportunity for this study to explore perspectives of family members in the current UK context.

1.8 Rationale and Aims

Rationale

Whilst it is recognised that an average of five people are bereaved following a death (Beuthin et al., 2022), it has been identified that this is higher in death by suicide, due to a *"ripple effect"* of impact (Maple et al., 2016). It has been suggested that for every suicide, between six and 135 people are affected (Cerel et al., 2019; Drapeau & McIntosh, 2017). Given that the SLR identified associated stigma between (non-assisted) suicide and assisted dying, it is likely that assisted deaths may also have a wider impact than 'natural' deaths. As such, it is important that the perspectives and needs of those impacted are better understood. Furthermore, it has been identified that family members may have differing views around assisted deaths (Emanuel et al., 2000; Gamondi et al., 2018; Ganzini et al., 1998; 2006), but research into families' perspectives on assisted dying is still limited and their needs within this context are rarely acknowledged (Goldberg et al., 2021; Roest et al., 2019; Snijdewind et al., 2014).

Previous research into assisted dying has primarily focused on an individual's reasons for choosing an assisted death (e.g., Chapple et al., 2006) with a minority of studies looking at why family members feel the individual made this decision (e.g., Ganzini et al., 2008).

However, interest into family members' perspectives more directly appears to be growing (Gamondi et al., 2019), noting the importance of their roles in decision making and providing support (Fujioka et al., 2018; Kimsma & van Leeuwen, 2007), and that relational influences can have an impact on the process (Variath et al., 2020).

Gamondi and colleagues (2019) identified that the involvement of family members in the assisted dying process may be influenced by factors such as morals, cultural factors, legal requirements in the country they are based, and their perceptions around the social acceptability of assisted deaths. This indicates the importance of understanding the perspectives of family members based in countries in which assisted dying is not legal (and therefore less likely to be socially acceptable) in order for services to be able to provide appropriate support to these individuals within this challenging context. These suggestions are reinforced by more recent calls for family members' needs to be supported (Goldberg et al., 2021), and to be better accounted for in health policies and care planning (Brooks, 2019; Council of Canadian Academies, 2018; Elmore et al., 2018; Fujioka et al., 2018; Roest et al., 2019).

Research that has looked at the impact on family members focuses mainly on bereavement (e.g., Beuthin et al., 2022; Srinivasan, 2019) and predominantly involves spouses, not other family members (Goldberg et al., 2021). This has resulted in calls to better understand the perspectives of different family members after an assisted death (Srinivasan, 2019).

Despite calls for further research, to my knowledge, there is currently no published research looking to understand the perspectives of UK-based family members affected by an assisted death(s). However, I am aware of a proposed study that appears to be focusing on UK-based families experiences of bereavement following an assisted death (Fish, 2017).

Given that Clinical Psychologists work with people and their families impacted by unbearable suffering, when an assisted death may be considered, it is important to understand family members' perspectives and factors influencing these in order to know how best to support affected families. This knowledge may also be able to contribute to the ongoing debate about legalisation and the support provision needed within the UK.

Aims

The following study aims to address the gaps in the literature around UK-based families' perspectives on assisted dying, and the contexts, views, and factors that inform and surround these perspectives. This study will build on earlier work on this topic, and hopes to complement the proposed research of Fish (2017), achieving a richer understanding of families' perspectives on assisted dying, outside of bereavement, and increasing diversity of the sample (by using additional recruitment strategies; see Chapter 2).

The main research question for this study is;
What are UK-based family members' perspectives on assisted dying following the assisted death of a loved one?

The sub-questions for this research are:

- What contextual factors influence these perspectives?
- How do these experiences fit with family members' prior views on death and dying?
- What resources do families draw on to navigate this period?

Chapter 2: Methodology

2.1 Chapter overview

This chapter will describe the methodology utilised throughout this project, including the rationale for undertaking a qualitative approach, the consultation process in the design of this research, recruitment of participants and processes for data collection and analysis.

2.2 Design

This study took a qualitative, cross-sectional approach, making use of interviews to gain an understanding of UK-based family members' perspectives on assisted dying. Qualitative designs are an important component of exploratory research, seeking to understand more about under researched phenomena (Denscombe, 2017). Qualitative research focuses on increasing the depth, rather than breadth, of understanding of a phenomenon, through understanding individuals' lived experiences in their specific contexts (Palinkas et al., 2015). Informed by perspectives such as postpositivist, critical and post-structural (Cypress, 2015), qualitative research identifies social phenomena as multifaceted (thus not able to be reduced to numerical variables) and 'knowledge' as socially and psychologically constructed (thus 'reality' never able to be objectively understood). This suggests that the focus of research should, therefore, be on gathering different understandings of reality. Alternatively, quantitative research, which draws on objectionist epistemology, seeks to gather data intended to offer a 'true' understanding of an objective reality (Yilmaz, 2013). Mixed methods approaches draw on both quantitative and qualitative data (Ivankova & Creswell, 2009).

2.2.1 Interpretative Phenomenological Analysis (IPA)

IPA was identified as an appropriate means to analyse the data collected from interviews due to being derived within the field of health psychology (Smith et al., 1999) and therefore appropriate to this field of research, and being theoretically rooted in critical realism (Bhaskar, 1978), the epistemological position taken for this study. It focuses on how people understand major life experiences (e.g., the death of a family member), offering the opportunity for individuals to share detailed accounts of their perspectives on a topic (Pistrang & Barker, 2012), with emphasis placed on the meaning created and sense made from these experiences (Smith & Osborn, 2015).

IPA is centred around three theoretical orientations: *phenomenology, interpretation,* and *ideography* (Smith et al., 2009). Phenomenology is generally understood as the study of human experience, however the nature of this has been interpreted differently by different philosophers. Husserl (1927) argued that it involves *“stepping outside of our everyday experience”*, and shifting gaze, with the focus needing to be on how we perceive objects through the use of reflection (to allow us to understand our own subjective experience of phenomena), rather than being focused on looking at the objects themselves. Whereas Heidegger and colleagues (1962) suggested that the ‘dasein’ (the human way of being in the world) cannot be removed from its various contexts (e.g., social, political, cultural) and therefore all human experience is temporal and perspectival (Draucker, 1999; Orbanic, 1999; Small, 2017). Merleau-Ponty (1962) echoes this position, particularly around the situational nature of knowledge but, rather than focusing on the ‘worldliness’ of experience, focused on our ‘embodied’ experience of the world; our bodies as being a means of communicating with the world rather than as an object within it. Finally, the philosopher Sarte contributes another layer of understanding to phenomenology concluding that experience must be understood in the context of the presence and absence of others; our relationships (Smith et al., 2009). In summary, the understanding of phenomenology used for this study is that it invites us to study ‘experience’ through connecting perspectives, meaning, and a person in their embodied context. However, interpretation is needed in order to comprehend someone else’s understanding of the world; in IPA this is guided by the theory of hermeneutics (Smith et al., 2009).

Hermeneutics are concerned with how and why interpretation is used. Schleirmacher made the distinction between a *grammatical* (or objective) reading of a text and a *psychological* interpretation; holding the text in its temporal, cultural, and individual contexts (for both the author and the interpreter; Smith et al., 2009). This is particularly relevant to the topic of this research, given the everchanging landscape of assisted dying globally and within the UK, the multitude of cultural factors that may inform perspectives on this topic, alongside individual experiences of relevant factors, such as unbearable suffering and death (see Chapter 1 for further context). Schleirmacher also suggested that intuitive, psychological interpretation is essential for meaning making, allowing IPA researchers to offer meaningful insights, through connecting with the aspects of shared humanity with the individual being interpreted. This process allows the interpreter to extend the individual's understanding of their experience and offer a new perspective on the phenomenon discussed (Schleirmacher, 1998).

Heidegger (1962) advises caution regarding the subjectivity of interpretation; interpretations are made in the context of the subjective life experiences and assumptions of the interpreter (their 'fore-conceptions'). This serves as a reminder about the role of 'bracketing' (removing the interpreter's preconceptions from the research; Gearing, 2004) in qualitative research and the importance of self-reflexivity for the researcher, given that bracketing is unlikely to ever be fully achieved. As such, in this research, the researcher has made use of a reflective diary throughout the process to support self-reflexivity (see Appendix A for extracts). Gadamer (1989) was concerned with the historical and traditional contexts of interpretation; seeing interpretation as a way of connecting the past (old preconceptions) and present (text being interpreted); and the dynamic process between the two. This connects with the notion of the 'hermeneutic circle'; the dynamic relationship between the 'whole' of the data and it's 'parts'. This reminds IPA researchers of the different 'levels' in which we may connect with data (e.g., a word, sentence, the interview as a whole), and the different meanings these may offer. As such, there is a need for the process of analysis to be iterative so that our relationship with the data can connect with all levels of the hermeneutic circle (Smith et al., 2009).

The final element of IPA is idiography; the promotion of individual experiences over nomothetical generalisability (Smith & Osborn, 2015). IPA strives for a detailed and particular understanding of a phenomenon from individual perspectives, making use of small sample sizes. However, the focus on the 'particular' should not be conflated with the focus being on an individual; IPA sees phenomena as relational and global. Therefore, IPA findings are seen as not discrete to, but the perspectives of the individual. This suggests that, whilst IPA findings are not purely generalisable, *"delving deeper into the particular takes us closer to the universal"* (Smith et al., 2009, p. 31). This is helpful in considering the usefulness in dissemination of IPA findings, especially in the context of Clinical Psychology service provision. It is particularly relevant to this research as, although these in-depth understandings are individuals' perspectives, situated in individual contexts, they offer an opportunity to understand the wider needs of this marginalised population within the everchanging landscape of assisted dying in the UK.

2.2.2 Consideration of other approaches

When considering the approach for this research, it was important to reflect on the focus of the study (Harper, 2011). Given the limited knowledge base in this area, ensuring that little heard perspectives on assisted dying were at the forefront of this research was important, and the chosen approach needed to support this. The ability to use the findings to start a conversation about how we can best support family members affected by an assisted death(s) was another ambition. These two goals, alongside pragmatic constraints, ultimately informed the decision to use IPA. Other qualitative methodologies that were considered are detailed in Table 6, alongside why each was not chosen.

Table 6 – Other qualitative methodologies considered

Qualitative methodology	Description	Why not chosen
Narrative analysis (Gee, 1991; Kirkman, 1997; Riessman, 1993)	A method focused on storytelling and how/why individuals' present these stories of themselves (in the context of identity development and life chronology; Linde, 1993).	I decided against this approach as I felt that the focus of this research was not on how and why stories are told, or about understanding an experience in the context of life chronology, but more about individual meaning making of a life experience.
Thematic analysis (Braun & Clarke, 2006)	*"A method for recognising and organising patterns in content and meaning in qualitative data"* (Braun & Clarke, 2006, p. 84).	I decided against this approach as I felt that it moved away from individual experience and meaning making which felt crucial to this subject area. It also requires a larger number of participants which didn't feel pragmatic given the anticipated recruitment challenges.
Individual case study (Starman, 2013)	A method focused on the *"comprehensive description of an individual case and its analysis; i.e., the characterisation of the case and the events, as well as a description of the discovery process of these features that is the process of research itself"* (Mesec 1998, p. 45).	I decided against this approach due to my ambitions for this research to inform service provision. As such, I felt that the opportunities to collect perspectives from multiple families was more valuable.

2.2.3 Expert by experience consultation

Individuals with lived experience of a family member having an assisted death were consulted when designing this research, informed by the phrase *"nothing about us without us"* (Charlton, 1998). These individuals were named an *'Expert by experience'* (EbE); a label given to acknowledge the expertise they hold through this experience.

EbEs were sought via advertisement on social media using a poster (Appendix B) and contact with campaigning organisations within the UK. However, making these connections at the early stages of this project was more difficult than anticipated. Given the sensitive nature of the topic, and legal status in the UK, some organisations were not prepared to contact their members until the project had received ethical approval, and social media advertising for these roles was not fruitful. However, I was able to identify three individuals through personal connections, and another via a contact within one of the campaign organisations, who were willing to offer their valuable expertise to the project. At the design stage, this involved consultation on the language used in recruitment material and review of the interview schedule. My reflective diary was used to reflect on the nature of the EbE-researcher relationship and evaluate the impacts these personal connections might have in this (Appendix A).

EbEs were remunerated with vouchers for contributing their time to the project. However, following the introduction of the 'Agreement for volunteers & lay members involvement in research' (Appendix C), a requirement of the University of Hertfordshire, only one EbE remained involved in the project after the design phase. This is likely due to the formality of this process, suggestive of an employment contract; perhaps incongruent with hopes of supporting the project in an informal ad-hoc way. Further involvement of the EbE that did remain involved in the project is detailed in relevant sections of this report.

Secondary sources of information were also used to inform project development. This included reading material developed by campaign organisations (both for and against assisted dying), and informal conversations with team members of organisations who, almost all, had personal connections to someone who had an assisted death or to relevant research. These conversations were vital for considering ways that connections could be built within this somewhat undercover network of people. I also attended a debate entitled '*Assisted Dying Should Be Legalised'* by the forum Intelligence Squared (https://intelligencesquared.com/), had a multitude of informative conversations with a member of the team at Dignitas and kept up-to-date with the latest news and media about assisted dying in the UK to continuously inform my thinking.

2.2.4 Semi-structured interviews

Semi-structured interviews were used to collect data, in line with IPA methodology. These allowed information to be gathered that was relevant to the research questions, whilst still offering the opportunity for interviewer discretion in exploring aspects of the responses further, particularly if unforeseen information was shared (Adams, 2015). Interviews allow for a deeper understanding of individuals' experiences (Smith et al., 1999), and fit with a critical realist epistemological approach, as this approach views communication through speech and behaviour as a reflection of differences in meaning making (Smith & Osborn, 2015).

When developing the interview schedule, an initial draft was constructed by the researcher and then reviewed by EbEs, and subsequently adapted, as opposed to the hopes for a co-produced version from the start. This was due to the time commitment required to build the necessary relationships to facilitate recruitment of EbEs in such a sensitive area of research, combined with the time pressures for completion of the research. Subsequent to review of the interview schedule with EbEs, adaptations were made. These included; the language used (given the sensitive nature of the questions) and the need to provide clear explanations as to why some questions were being asked (due to hypervigilance participants may feel when attending the interview due to the illegal nature of assisting deaths in the UK). The final interview schedule (Appendix D) was used in a pilot interview with one EbE, so that the researcher could practice question delivery and navigate any challenges posed by the interview ahead of the research interviews.

2.2.5 Ethical approval

Ethical approval was obtained from the University of Hertfordshire's Ethics Committee, via the Health, Science, Engineering and Technology ECDA (ref: LMS/PGT/UH/04982; see Appendix E). When designing the study, a multitude of ethical issues were considered, which are detailed below. Following ethical approval, a number of amendments were made to this ethics application due to issues with recruitment (see section 2.3.2).

2.2.6 Informed consent

The participant information sheet (Appendix F[5]) provided potential participants with information about the project and clearly detailed the process for consent. Once individuals had made contact with the researcher, opportunities to ask questions about the project were offered; either over email or by phone. They were also informed of their rights to withdraw from the project. Following this, informed consent was provided by willing individuals via a signed consent form (Appendix G). Individuals were only invited to an interview once a signed consent form had been received by the researcher.

2.2.7 Confidentiality

Confidentiality and anonymity were also explained in the participant information sheet and consent form, as well as in informal discussions. This was also reiterated at the start of the interview with participants.

Participants were informed of the limits of confidentiality; particularly around appropriate action being taken if the participant became distressed in the interview (e.g., containing the emotion within the interview, suspending the interview, signposting the participant to further support, or breaking confidentiality and taking immediate action to ensure their safety by engaging emergency services). Information regarding breaking confidentiality due to disclosure of illegal information was also provided (see section 2.2.8).

Interviews were audio-recorded on a Dictaphone. The file was then transferred to a private computer, within 24 hours of the interview, and deleted from the Dictaphone. Upon transcription, all identifiable information was anonymised and the recording deleted.

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[5] Please note that all participant materials shared in the appendices are the final versions from after the second amendment to the ethical protocol was approved (see section 2.3.2). The only difference between versions is the protocol number and the time since the assisted death.

2.2.8 Navigating the legal status of assisted dying in the UK

Given that at the time this research was undertaken, assisting someone to die (and therefore ‘assisted dying’) was illegal in the UK, much consideration was given as to how this research could take place within this context and what adaptations were needed. These conversations were supported by one EbE, based in the UK, who had experience of navigating these parameters when her family member had an assisted death.

It was necessary to balance ensuring that this research was working within the law, but also that participants felt safe to take part. Therefore, in order to have a clear way of navigating these conversations, and in line with a request from the Ethics Committee, I developed a Disclosure Protocol (Appendix H). This clearly stated the steps I would take if it appeared that someone participating in the research might make a disclosure about, so called, ‘illegal activity’. For this study ‘illegal activity’ was defined as;

“A participant in the study disclosing information relating to their involvement in practically assisting the death of their family member. This includes a participant sharing that they have obtained strong sedatives for someone, knowing the person intend(ed/s) to use them to kill themselves or that the participant accompanied a person to an organisation, such as Dignitas, for an assisted death. However, this does not include conversations about ones wishes with loved ones”.

This was discussed with participants at the beginning of each interview so that they were aware of the limits of our conversation. I also ensured to state in the participant information sheet, and at the start of the interview, that I was solely interested in hearing about participants’ *perspectives* on assisted death and would not be asking about what had happened around their family member’s assisted death. In the practice interview, the EbE and I discussed the nature of the questions I was asking and agreed that they limited opportunities for disclosures of this type.

I noticed that navigating this context within the research process connected me with my dual identity as a researcher and an NHS professional; and therefore, my duty of care. However I also noted the impact of my own views on this topic; feeling that family members should not be implicated by supporting the wishes of their loved one, and therefore wanting to be supportive in these conversations. I worked hard to strike this balance across interviews.

2.2.9 Comfort of participants

Given the challenges identified in section 2.2.8, the sensitive and emotive nature of this topic, and potential for distress during interviews, participants were given the option of sharing their experiences in a way that felt most suitable to them (e.g., face-to-face, video-call or telephone-call; Deakin & Wakefield, 2014; Heath et al., 2018). This also supported the accommodation of varying needs wherever possible. They were also given the opportunity for breaks and to do the interview in shorter sessions if they wished to. Discussions around this ahead of the interviews were informed by the work of Dempsey and colleagues (2016). For details of the post-interview support offered, see section 2.3.5.

2.3 Data collection

2.3.1 Sampling strategy

Smith and colleagues (2009) report that IPA is appropriate for studies with a sample size of 2-25 participants. When considering aims for sample size, the scope of and hopes for this project were considered. It was acknowledged that it was being completed as part of the Doctorate in Clinical Psychology training (DClinPsy), and therefore the need to be pragmatic about the impacts of course restraints on recruitment. Furthermore, expected recruitment challenges were identified due to the sensitive topic (Dempsey et al., 2016), the legal status in the UK, and the specific inclusion criteria, which also suggested a need to be conservative about recruitment aims. Therefore, this study aimed to recruit between six and eight participants (Turpin et al., 1997), and a maximum of 15 participants. It was hoped that this would make it possible for this research to valuably contribute to the literature on this topic, whilst being realistic about the identified challenges.

2.3.2 Inclusion criteria

Inclusion criteria for this project were discussed in depth with supervisors and EbEs for the project. Participants were initially required to be adult, UK-based, family members, of someone that had an assisted death outside of the UK within the last four months. For both participant and researcher safety, it was also required that participants were not involved in any ongoing police investigations. Table 7 details these criteria and the rationale for each.

Table 7 – Initial inclusion criteria for participants

Inclusion criteria	Detail	Rationale
Age	Participants were aged over 18 years old.	This is the legal age denoting someone as an ‘adult’ in the UK. This was used due to the sensitive topic and ethical implications for including children in research.
UK-based	Participants identified as living in the UK.	This study was wanting to understand the perspectives of family members navigating the UK landscape of assisted dying.
Definition of ‘family member’	Participants self-defined as family members of someone who had an assisted death outside of the UK.	It was considered important that individuals self-identified in this way, so as not to impose western ideologies around what ‘family’ is on the outcomes of this research (Goldner, 1985), as family, for many, can cross biological parameters (e.g., including friends, neighbours and carers; Kristjanson & Aoun, 2004; Roest et al., 2019).
Location of the assisted death	The assisted death of participants’ family members had taken place at an established assisted death organisation outside of the UK (in a country where this was legal).	This was imperative to safeguard both the participant and the researcher as, at the time of data collection, assisted death was not legal in the UK.
Time since assisted death	At the time of interview, the assisted death of participants’ family members had taken place within the last four months.	This timeframe was initially agreed due to the impact of time on memories. Studies have shown that autobiographical memory works by reconstructing memories, rather than recollecting an exact representation of the events that took place. As such, an individual’s current situation can inform recall in memories through connecting the *“remembered and remembering self”* (Josselson, 2009) and *‘‘adjust[ing] the past to the demands of the present and the anticipated future’’* (Bruner, 2003, p. 213). Research also suggests that individuals are more able to recall memories accordant with their current sense of self (e.g., Conway & Holmes, 2004; McAdams, 1993). Given that identity can be impacted by historical, relational, and culturally bound contexts (Combs & Freedman, 2016), this may influence what participants share, depending on the time since death. This fits with the theoretical underpinnings of IPA, noting the importance of research being temporally situated (Draucker, 1999; Orbanic, 1999; Small, 2017).

		Participant wellbeing during a period of grief was paramount when making this decision. Studies looking at grief post assisted-death suggest that anticipating the death (as the death is planned), means that ‘anticipatory grief’ (i.e., processing) has often taken place before the death (Srinivasan, 2019). Srinivasan (2019) also found that having control over the death, knowing that a loved one avoided suffering and experienced a comfortable death (in contrast to the possible alternative), positively impacted participants’ experiences of grief. This was aided by the opportunity to say goodbye, which is often not possible when someone dies (Holmes et al., 2018; Srinivasan, 2019). Where participants have found the assisted death less of a positive experience, or where a lack of social approval of this way of dying has had a negative impact on wellbeing (Wagner, Müller & Maercker, 2012), it could be suggested that offering willing participants the chance to talk about this in an open, non-judgemental space is likely to be cathartic as opposed to detrimental.
Legal status	That participants are not involved in an ongoing police investigation related to their involvement in their family member’s assisted death.	As above, this was imperative to safeguard both the participant and the researcher as at the time of data collection, assisted death was not legal in the UK.

Over the course of the research, amendments to the criteria ‘time since assisted death’ were required due to significant recruitment issues despite exhausting available recruitment channels. In consultation with supervisors, stakeholders and an EbE, in December 2022, having recruited no participants, this timeframe was increased to within one year since the death. This decision was made in the hope of still maintaining the research aims and reasoning for the initial timeframe, but allowing further scope for recruitment. However, following further recruitment issues, and due to the time constraints of the research, another amendment was made in March 2023 to increase the time to within five years (see Appendices I and J for confirmation of ethical approval of these amendments).

This decision was made to support recruitment of a sufficient number of participants (deemed to now be a minimum of five participants; Larkin et al., 2021) and informed by access to the latest figures from Dignitas for 2022 (made publicly available in March 2023). Figures showed that only 33 UK citizens used their services in the last year; compared with, for example, 42 in 2019 (Dignitas, 2023b). Expressions of interest had also been previously received from people interested in taking part, but who did not meet the original criteria regarding timeframe. The need to be pragmatic about possible ongoing recruitment struggles was identified, noting that *“even a single case study can yield rich and interesting results if the topic is complex and the data rich”* (Smith & Nizza, 2022, p. 15).

Whilst it is acknowledged that conducting interviews up to five years since the assisted death may appear to conflict with the directive for the initial timeframe, as there is currently no research published in the UK on this topic, it was felt that offering UK-family members a platform to share their perspectives should take priority.

2.3.3 Recruitment

All participants self-selected to take part in this research. They were obtained through purposive sampling (a method of sampling *“used to select respondents that are most likely* *to yield appropriate and useful information"* that are connected with the phenomenon of interest; Kelly et al., 2010 p. 317) in the context of limited research resources (Palinkas, 2015). Opportunity sampling was also attempted; however this was not successful.

With hopes of accessing family members with a range of possible demographics and perspectives on assisted dying, this study planned to extend the proposed recruitment strategy of Fish (2017); the only other known (ongoing) study involving UK-based family members of people who had an assisted death. Similarly to Fish (2017), recruitment was undertaken via the campaign organisations; My Death, My Decision (www.mydeath-mydecision.org.uk) and Dignity in Dying (www.dignityindying.org.uk). Additional recruitment strategies utilised in this study were via the social media platform Twitter (www.twitter.com) and the assisted dying organisation, Dignitas (via their mailing list).

Advertising the study on Twitter involved setting up a research-specific account and sharing a recruitment poster (Appendix K) asking anyone interested to contact the researcher via a university email address for information. Recruitment via the campaign organisations involved building relationships with gatekeepers of the organisations ahead of recruitment, before asking them to share the study information (the poster alongside the participant information sheet) with their members. They reported sharing study information with individuals within their network via Facebook groups and their Twitter account.

The final recruitment method was via Dignitas, made possible by an established relationship with the Dignitas team ahead of recruitment. This recruitment took place in three stages (see Table 8). It involved the Dignitas team sharing the participant information sheet and a letter specific to Dignitas recruitment (Appendix L) with their UK-based mailing list, asking people to make contact with the researcher directly if they were eligible and interested in taking part. Between recruitment calls via Dignitas, the researcher continued to seek participants via the other approved methods.

Table 8 – Dignitas recruitment process

Recruitment stage	Date	Time since assisted death eligibility criterion	Approximate number of emails sent	Expressions of interest received
1	August 2022	Within 4 months	1200	135
2	December 2022	Within 1 year	1355	19
3	March 2023	Within 5 years	1472	12

It is noted that, whilst recruitment was expected to be challenging (given the sensitive topic and the impacts of the legal status of assisted dying in the UK on conducting this research), the number of responses to these recruitment calls was overwhelming. Across three Dignitas mailings, I received 166 email responses (representing just over 11%[6] of those contacted). Despite email recruitment in qualitative research being documented as having varying levels of success (Sledzieski et al., 2023), this is much higher than the average response rate for email recruitment which has been identified as 1% (Koo & Skinner, 2005). Although the majority of these individuals that made contact did not meet the study's inclusion criteria, the vast number of responses from people not eligible but choosing to share their story or support, suggests just how many people want this topic to be talked about and their story to be heard. This in itself suggests that more research on this topic is needed.

2.3.4 Final sample

Five participants were recruited to this project and took part in an interview with the researcher. All five participants were recruited from Dignitas' recruitment mailings. Please see Table 9 with information about participant demographics.[7]

Table 9 – Participant demographics

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[6] Please note that this is based on the assumption that each email address is equivalent to an individual member and does not account for any possible inconsistences in the mailing list or figures provided by Dignitas.

[7] Please note that due to the small sample size, and limited population, exact details (e.g., exact time since assisted death) have not been shared to maintain participant confidentiality.

Age	Gender	Self-defined ethnicity	Self-defined religious orientation	Relationship to family member who had assisted death	Felt 'involved' in discussions that led to the family member's assisted death? (Yes/No)	Approximate time since family member's assisted death
75	Male	White British	Christened (but not attending church)	Father	Yes	< one month
79	Male	Anglo Saxon	Church of England (but not religious)	Husband	Yes	< one month
66	Male	White British	Liberal Unitarian / Ecocentric	Husband	Yes	4 months
80	Male	White - UK	None	Husband	Yes	47 months
70	Female	White	None	Daughter	Yes	56 months

2.3.5 Interviews

As a result of participant preference, two interviews took place in person, two interviews took place via telephone and one interview took place over Zoom. All participants were at home for the duration of their interview. During the recruitment period, thought was given to participants being given the choice in mode of interview and the practical challenges this may have posed (see Appendix A for reflective diary extract). In all interviews, participants were encouraged to find a space that they felt comfortable to talk in, and when interviews took place via Zoom or telephone, the researcher let participants know that she was in a confidential space in which the interview could not be overheard. Four of the interviews were conducted with only the researcher and participant present and one interview was conducted with a participant's friend also present. This was requested by the participant at the time of the interview for support, given concerns about the interview being conducted within the current legal status in the UK. The friend was asked by the researcher not to contribute to the content of the interview; to ensure that the participant's views only, were captured. Verbal consent was gained from the friend to confirm that they were happy to be present for the interview, noting that should they speak during the interview, that their contribution would be included in the audio recording. The limited verbal contributions of this friend were not included in the transcription or analysis as they were not deemed to be perspectives of the participant who had consented to take part in this study.

The semi-structured interview schedule was used as a guide for interviews, with further questions used based on researcher discretion. Interviews lasted between 53 and 114 minutes. Data storage procedures were followed (see section 2.2.7).

During interviews, participants were initially asked questions from the pre-interview questionnaire in order to collect a range of demographical information and initial facts about the assisted death of their family member, and to specify their relationship to them. This information was collected at the start of interviews as the disclosure of personal data is more likely when participants are assured of confidentiality and when rapport is built (Wellings et al., 2000). For the remainder of the interview, participants were asked a variety of questions relating to the different contexts that surrounded their family members' assisted death, the impact of the illegal status of assisted death in the UK, the meaning they have made, and how all of these may have contributed to their perspectives on assisted dying. Participants were also asked about the resources they have drawn on to navigate this period.

At the end of the interview (if in person, or by a follow-up email otherwise), participants were provided with a debrief sheet outlining the study aims and some options for support should they want to access it (Appendix M). As requested by the ethics committee, participants were also offered a check in with the researcher within 24 hours of the interview, however none of the participants took up this offer. Following each interview, I made use of my reflective diary to share reflections on the interview process (e.g. reflections on the participant-interviewer relationship and why I might have been drawn to particular aspects of the interview). These were drawn upon during the analysis stage.

2.4 Data analysis

2.4.1 Transcription

The researcher transcribed all five interviews. A verbatim transcript was produced for each interview, focusing on the content of the interview, rather than prosodic aspects of the recordings that might be required for other methods of analysis (Smith & Nizza, 2022). This allowed the researcher to become familiar with the data and to fully anonymise it (e.g., removing any names and locations that may contribute to a confidentiality breach).

2.4.2 Analysis

The stages of IPA outlined by Smith and Nizza (2022) were utilised for analysis. Each transcript was reviewed and analysed individually. Although the process was not linear (and involved constantly moving between the individual part and the whole of the data for each interview), the broad steps that were followed were:

1. Initial multiple readings of the transcript and recording of exploratory notes. These focused on descriptive, linguistic, and conceptual elements of the data alongside initial interpretations.
2. Formulating experiential statements. This focused on summarising each speaking turn of the participant, including the psychological substance of what was being shared.
3. Finding connections and clustering experiential statements into Personal Experiential Themes (PETs), asking *“what should go with what?”* (Smith & Nizza, 2022, p. 43).
4. Compiling a table of PETs for that individual.

Examples of this analysis process are evidenced in Appendices N (steps 1 and 2) and O (the outcome of step 3 and step 4). These stages were repeated for each of the five interviews, before engaging in cross case analysis of the five sets of PETs, resulting in a set of Group Experiential Themes (GETs) for the overall data (see Chapter 3).

At all stages, I engaged in reflexivity, considering how it felt conducting the interview, my felt relationship with the participant, and the interactions between our similar and differing Social GRRRAAACCEEESSS (Burnham, 2018; Pietkiewicz & Smith, 2014). I also reflected on the ‘double hermeneutic’ and how *“the researcher is trying to make sense of the participant trying to make sense of what is happening to them”* (Smith et al., 2009, p. 3), and how these contexts, as well as other contexts (e.g., my position to the research) may have been informing my interpretations.

Whilst the interpretative nature of IPA meant that formal ‘member checking’ was not considered appropriate (Larkin & Thompson, 2011), it felt important that patient and public involvement (PPI) was utilised at all stages of the project, and that participants had an opportunity to feed back on the results. As such, the final results were collated into a summary document (see Appendix P) which was shared with all participants (as they had all consented to this contact on their consent form) asking that they share any feedback with me via email, should they wish to do so. This document was also shared with one EbE. Responses to this summary ranged from *“very ‘generalised’…not hard hitting enough”* to *“a brilliant summary”;* suggestive of possible different hopes/intentions for taking part in this research.

2.4.3 Quality assurance

Quality standards were considered when conducting this research and the quality of this study was assessed using the same CASP tool used in section 1.7.4 (CASP, 2018). This involved seeking to meet the research aims through the data collected, appropriateness of design, methodology and recruitment strategies, considering the researcher-participant relationship and the positionality of the researcher, and the ethical issues involved in conducting this research. In relation to the findings, consideration was given to the quality of the analysis process, clarity around findings and a demonstration of the value in this research. Please see Table 10 which details the assessment outcomes. These suggest that despite the challenges faced when conducting this research, the attempts to be transparent about all aspects of the research process (e.g. how the research was conducted, detailing the challenges faced, and sharing insights into researcher positionality) and the possible impacts these may have had on outcomes, allow the study to be seen as trustworthy and as still offering valuable contributions to the literature on this topic.

Table 10 – Results of critical appraisal of the quality of this study

CASP Appraisal Checklist
(Yes = criteria met, no = criteria not met, can't tell = unclear whether criteria has been met)

No.	Criteria for Quality	Criteria met?	Evidence for meeting the criteria
1	Was there a clear statement of the aims of the research?	YES	The aim of this study was to explore UK-based family members' perspectives on assisted dying. This aim is stated in section 1.8.
2	Is a qualitative methodology appropriate?	YES	A qualitative methodology was considered appropriate for this study given the focus of seeking to gather rich, in-depth descriptions of family members' perspectives. Semi-structured interviews allowed the researcher to gather relevant data to the research questions, whilst also offering flexibility to follow-up participants' responses with further questions as needed.
3	Was the research design appropriate to address the aims of the research?	YES	A qualitative design was deemed appropriate as per Q2. IPA was selected as the analysis method due to its focus on detailed accounts of participants' experiences and on individual meaning making (Pistrang & Barker, 2012). As the SLR found that there is no published literature on UK-family members' perspectives on assisted dying, IPA was felt to be an appropriate method to gather initial understandings of an under-researched topic.
4	Was the recruitment strategy appropriate to the aims of the research?	YES	The project attempted to use both opportunity and purposive sampling, although opportunity sampling was not successful. Purposive sampling inevitably made it possible for the researcher to locate appropriate participants from this somewhat 'hidden' population.
5	Was the data collected in a way that addressed the research issue?	YES	Data was collected by conducting semi-structured interviews. Participants were offered the opportunity to choose interview modality (in person, via Zoom or telephone) to aid comfort due to the sensitive nature of the phenomenon being researched and legal status. The data collection method enabled participants to share their perspectives, whilst also being guided by the interviewer. Please see section 2.3.5 for more information.
6	Has the relationship between the researcher and participants been adequately considered?	YES	The positionality of the researcher was discussed early on in this report (section 1.3) as a way of prioritising transparency about the researcher's (ever-changing) relationship to this topic. A reflexive approach was used throughout this research project, including the use of a reflective diary,

			consultation with supervisors, consultation with EbEs, sharing evidence of the analysis process (see appendices N and O) and remaining grounded in the data (Larkin & Thompson, 2011).
7	Have ethical issues been taken into consideration?	YES	Ethical issues were considered at length when designing this project and through dialogue with the ethics committee and Experts by Experience when seeking ethical approval. See 2.2.5 to 2.2.9 for details. A risk assessment of the multitude of possible risks for consideration was conducted. This study was approved by an Ethics Committee. Two amendments to the project's ethics application were made due to recruitment issues in the project (see section 2.3.2).
8	Was the data analysis sufficiently rigorous?	YES	A rigorous approach to data analysis was taken, following an established IPA framework, as detailed in section 2.4. The analysis involved reviewing each interview individually and undertaking a multi-staged process of making exploratory notes, formulating experiential statements, and collating these experiential statements into PETs. This was not a linear process and involved many iterations of each stage to ensure rigour. Cross case analysis for the five sets of experiential statements allowed the development of the final GETs described in Chapter 3.
9	Is there a clear statement of findings?	YES	There is a clear statement of the findings at the start of Chapter 4 which is related to the main research question and sub-questions.
10	How valuable is the research?	YES	This study is the first known study to explore UK-based family members' perspectives on assisted dying, and is the first study speaking to family members of people who have had an assisted death where assisted dying is not legal. The study's findings contribute to global literature on assisted dying, by offering perspectives from a country where assisted dying is not legal, and where the individual choosing the assisted death has had to seek this service abroad. This research particularly offers insights into a range of contexts surrounding the choice for an assisted death and a range of associated perspectives on the topic. It is hoped that the results of this research may be helpful in informing the current debate on whether assisted dying should be legalised in the UK, and if it is legalised, the variety of factors that need to be considered in offering these services.

2.5 Dissemination

Throughout this project, consideration has been given to how the outcomes of this research may be disseminated. This has felt particularly important given the current debate about whether assisted dying should be legalised in the UK and possible uses this research might have in informing this.

Whilst undertaking this project, I attended a talk by Dignitas in London, whereby the Dignitas spokesperson presented information about assisted dying and the services they offer and facilitated a discussion about assisted dying more generally. This presentation and discussion was filmed, with the expectation that some of the footage gathered may appear in a documentary, due to be aired on UK television later this year. During this session, I was able to briefly discuss my hopes for this research, and have agreed to contact the documentary production team following the conclusion of this research, with the hope of considering opportunities for sharing the findings.

Furthermore, recently, the House of Commons Health and Social Care Committee of the UK government has been conducting an inquiry into assisted dying (UK Parliament, 2022b). Earlier this year, submissions were requested, and whilst this was prior to data collection, I was able make a submission which incorporated responses to specified areas of interest in the inquiry, and an acknowledgement that the results from this study will be available later this year. Post hand-in, I plan to investigate whether I can utilise this platform for dissemination.

Following the project’s conclusion, I also plan to reconnect with one EbE to discuss other possibilities for dissemination, and follow up ideas shared by participants when feeding back on the results. I plan to share the outcomes with the organisations that offered recruitment channels to this project, particularly Dignitas, as many individuals who emailed me to offer support of this project, identified they would be interested in understanding the outcomes of this study.

Chapter 3: Results

3.1 Chapter overview

This section will present the findings from IPA on the views on assisted dying of UK-based family members of someone that has had an assisted death. From this analysis, it is hoped that the reader will be given an insight into these perspectives on assisted dying.

Please note, this section represents just one interpretation of the data collected. It is inevitable that my ever-evolving relationship with this topic, and positioning as an 'other' researcher (see section 1.3), may have influenced interpretations. Furthermore, given word limitations, fuller accounts of what participants shared has not been possible, however I hope to do justice to the accounts I was gifted. All names utilised in this section are pseudonyms, to ensure participant anonymity.

3.2 IPA

Following IPA of the data collected, four Group Experiential Themes (GETs) were identified, each with a number of subthemes (see Table 11).

Table 11 – Group Experiential Themes and subthemes

Group Experiential Theme	Subtheme
1. A life dictated by illness	Life as "in-valid"
	The "burden" of caring
	When illness joins a relationship
	Death as a therapeutic goal
2. Life as autonomous	The right to choose
	Ready for the end
	Duty to support the decision
3. Navigating an "illegal" landscape	Being made to feel like a criminal
	Burden on healthcare professionals
	Sharing on a need-to-know basis
	Support on this journey
4. Assisted dying should be legalised	Assisted dying as part of modern medicine
	Issues around misuse

The GETs will each be presented separately, illustrated by verbatim quotes taken from participants' accounts.[8]

3.3 A life dictated by illness

All participants connected with the impact of their family member's medical diagnosis on current or perceived future impacts on their life functioning and quality of life. This theme attempts to acknowledge the complexities of these circumstances for both the individual and their family, and the different ways unbearable suffering can influence lives and result in the choice for an assisted death. Four related subthemes are discussed: 'Life as *"in-valid"', '*The *"burden"* of caring', 'When illness joins a relationship', and 'Death as a therapeutic goal'.

3.3.1 Life as "in-valid"

All participants reported believing that their loved one had chosen an assisted death due to the perceived worth of the life quality that they had been experiencing, or were anticipating experiencing, due to their medical diagnosis.

For those whose family member had been living with unbearable suffering prior to their assisted death, participants described witnessing the impacts of this suffering on their family members' perceptions of the meaning of their life. Robert shared that his wife had told him that her life felt *"in-valid"* due to feeling she had no quality of life;

"And I think she felt her role was, she was getting to stage where she couldn't see anything other than her role being as a full-time invalid. And in her, as she put it, being a full-time invalid, in her mind, meant in-valid, it was no, no life worth living". (Robert)

Which may have become worse due to the impacts of the restrictions on care during the Covid-19 pandemic;

"…her disabilities had got worse and worse…particularly in the last 2 years…almost to the day of lockdown starting…whether it's coincidence or not…she had to stop physio and things like that, and from then on her disability definitely got worse". (Robert)

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[8] For readability, repeated words, pauses and non-comprehendible utterances deemed not to be relevant to what the quote is illustrating have been denoted by '…'.

He shared that witnessing this unbearable suffering and choice for an assisted death connected him to other experiences of witnessing suffering, and his wider views around death in these contexts;

"…one of the first reactions to hearing my mum had died, was that it was relief…because I knew she was so…desperately unhappy. And…in such a…place of despair the whole time…when you see somebody, you know really suffering…maybe it…had an impact on the way I thought about [Name] potentially going for assisted dying…that I had some understanding that it is possible to be in a situation where you really feel your life isn't worth living". (Robert)

Witnessing this felt sense of *"in-valid[ity]"* was identified by other participants in different ways. Richard similarly perceived his son to have been experiencing unbearable suffering for some time, which he appeared to connect with the intensity of physical symptoms and the longevity of suffering;

"…he'd suffered since the age of 12 or 13, so he'd suffered for half his life with this…and it had gradually got worse…there were times when…he couldn't even speak…he felt so dreadful". (Richard)

Others described situations in which their family members' diagnosis brought anticipated unbearable suffering and believing that they had chosen an assisted death to pre-emptively avoid this. Martin described understanding his wife choosing an assisted death following her diagnosis as a way of avoiding the unbearable suffering she had witnessed in others. He also seems to suggest that knowing that she would not suffer in dying (by the natural progression of her terminal illness), had eliminated any worries about her future and allowed her to fully embrace her remaining time;

"She said that I've witnessed…women of her age group who've ended up in hospitals or hospices on endless cycles of chemotherapy, still with catheters and wires and drips and having a pretty awful death…and her thing was, I'd rather just live my life, continue painting, continue sculpting…and when I feel really bad then off I'll go to Switzerland…". (Martin)

Whereas Hannah described her mother's longstanding desire for an assisted death due to hopelessness associated with noticing cognitive changes, which suggested that her quality of life may begin to be compromised;

"…10 years before she died. She said, I want to go because…nothing gets better. It's this quality of life. It's not quantity of life...And when you're used to being…physically and mentally very fit…the mental deterioration worried her to death, because she knew it was happening". (Hannah)

3.3.2 The "burden" of caring

Participants shared the interwoven nature of this unbearable suffering and the impacts on them as a family member. They, however, appeared to grapple with identifying the challenges they faced, whilst also wanting to differentiate this from the unbearable suffering that had led their family member to choose an assisted death.

Robert acknowledged the constraints that being a full-time family carer brought for him;

"…I was her full-time carer…I couldn't leave the house for any period time…if I needed to go to the pharmacy…that might only take 20 mins…but either, we had to make sure that [Name] had been to the loo…or she would have to wait on a commode or…wear pads while I was out of the house…it would normally be two or three times a night, I would be woken up to help her…it was very much a…not a full-time, as in, you know, minute-by-minute, but it was a lot of it was, just being around…being on…call". (Robert)

Which came about as a result of the restrictions imposed during the Covid-19 pandemic;

"…during the, the full lock down…I was her only carer, because the carers who we had employed wouldn't come…". (Robert)

However, Robert also appeared to connect with a sense of guilt for feeling this way, differentiating the psychological constraints he still felt when external help was available, with the physical constraints imposed on his wife;

"…even though…I knew that what I was going through, I could still, you know, if one of the carers was here, I could still, you know, go down to the high street, or stop and have a coffee somewhere or...It might have been limited freedoms, but there was always, there was always the option of doing things like that, whereas, you know, [Name] sat in this space that I'm sitting in [tears] and her view of the world for most of the day was, you know, out in the garden…". (Robert)

Mark also identified the restrictions that caring posed to his quality of life, which he felt may have contributed to his wife's choice for an assisted death;

"…one of the reasons why my wife took the decision was that she had no quality of life…But one has to remember as well, that if she had no quality of life, it wasn't doing my quality of life any good either". (Mark)

He also identified a sense of *"freedom"* after her death, although appeared to find this difficult to verbalise;

"…it's a feeling of, of relief and…of, freedom…funnily enough – you know…not that I begrudge what I did for my wife at all, don't get the idea that I did, but I did it because…she needed it, and she needed my help and I…gave it to her…Umm, but, now…I've got to now look at what I'm going to do next". (Mark)

Whereas others, not in caregiving roles, shared views around the *"burden"* on others associated with being cared for, suggesting a belief that many people would not want this way of living;

"…most of us want to die while we are still fully in command of our faculties etc., and that we shouldn't be a burden on others". (Richard)

"…part of her decision was, she never wanted to be an…burden is a strong word…for somebody else to have to take the responsibility…She was never a parent who wanted in her old age for the child to look after her..."I had you, to have your life". (Hannah)

Across accounts, the hesitation to discuss this perceived *"burden"* suggests a sense of guilt that caring might be thought of like this, or worry about how feeling like this may be perceived. However, these accounts appear to agree on the perspective that caring for a family member can be challenging, but whilst some still viewed this as their responsibility, others appeared to not.

3.3.3 When illness joins a relationship

Participants also reflected on their family members' medical diagnoses joining their relationship. For Robert, his wife's caring requirements as a result of the symptoms of her diagnosis and the need to prioritise this care above his own relationship needs, appeared to leave him grieving the loss of their relationship;

"…the biggest difficulty is…how can you be a carer and be a partner as well?…The partner element, gets squeezed out because there just isn't the…bandwidth to…manage both…I'm not sure I understand Maslow's hierarchy of needs, but it almost feels like you step down a level from…if you're healthy in a relationship, then the relationship can…exist at an…emotional and physical level, but when it gets down to, a situation that requires so much care, you drop down to…it does become a grind…it made me, frustrated at times, bad tempered. Umm [Name] was full of frustrations…so. It was difficult then to have…the partner relationship". (Robert)

Whereas Mark, appeared to have found ways to distinguish the ways he offered care to his wife from the more practical elements of care offered by the professional carer, perhaps as a way of holding onto aspects of their relationship;

"…I'd get up at 6 o'clock, I'd go down and see the wife, I'd make her a hot drink…and then at 7 o'clock I'd go in there and help her clean her teeth, help her wash her face and anything else she wanted me to do. Umm, until 8 o'clock when the carer came down and then we moved her out of the bed umm onto err relieve some of her body functions or to bring her in here". (Mark)

Other participants, not in caring roles, appeared to believe that witnessing the unbearable suffering of their loved one had brought them closer;

"…we understood his struggles and…I think it sort of bound me closer to him…when you see your boy, and child having a hard time y-you naturally want to help…I had a child that was suffering and…that made me want to try even harder". (Richard)

"…although we lived these sort of separate um channels…we were very close…I think, during the time, if anything, we became closer…we talked an awful lot about what was ahead". (Martin)

However, Martin suggested that this closeness he felt, when on this journey together, made it harder when he was the one left behind;

"…for most of your married life you're trudging up a fairly st- sort of steep hill…then suddenly she'd come to the top of her hill and she could see the end point…And so obviously it makes a big change in your perception of life…I was wondering…how my life would follow without her". (Martin)

3.3.4 Death as a therapeutic goal

An assisted death was seen by some as the only way for their loved one to be relieved of their unbearable suffering. Richard noted the desperation to relieve his son's suffering. He appeared to feel, or at least need to believe, that at that point in time, all other options for relieving this suffering had been adequately investigated;

"…when you're a parent of a child that's in trouble or suffering…you have to, do whatever you can…if I thought…there was a…possible cure, some relief, and it meant flying to Timbuctoo, we'd have gone…we followed every single possible step we could…you know the, the most awful thing would be if er somebody in um America or somewhere sorta suddenly came up and said we've got a cure. You know that would be appalling, but it would be wonderful for all existing sufferers…". (Richard)

Mark similarly seemed to feel that death was the only way of alleviating his wife's unbearable suffering. However, he also appeared to be emphasising the subjective nature of unbearable suffering, suggesting that individuals' circumstances and reasons for choosing an assisted death are different and cannot be compared;

"…you will have different reasons for somebody wanting that…my wife's is quite simple…in some instances she was semi-paralysed and…she was in excruciating pain…it couldn't be relieved…I think…that is an outstanding case for having it…and yet, you see, disabled people, in paralympic games for instance, you know. Who, who, who conquer this. It's horses for courses". (Mark)

For others, who believed an assisted death had been chosen to avoid pre-empted unbearable suffering, appeared to view their family member having an assisted death as an opportunity for them to choose a *"happy"* death;

"My mother couldn't have been happier. Why doesn't everybody have that right? Most people are dying in agony or…the luckiest person on earth is the person who dies in their sleep when they're still healthy…". (Hannah)

For Robert, the confidence in believing that his wife had died happy, appeared to be a source of comfort to him;

"…it is important to feel that she did die happy. I don't think she was putting it on, I think she was genuinely…had made a decision and was happy with the decision". (Robert)

Moreover, for Martin, his perception that his wife had a positive death experience, appeared to make an assisted death even more appealing to him as an end-of-life option;

"…the more I think about my wife's death and the choice and her way of death, I become more and more enamored with it". (Martin)

These perspectives all seem to suggest that for some, in certain contexts, and/or within the limitations of other medical alternatives, death may be seen as therapeutic for some.

3.4 Life as autonomous

This theme felt like a central undertone to all conversations; a sense that individuals are responsible for, and should be able to, choose their own life path.

3.4.1 The right to choose

Participants all suggested that the right to make choices, and particularly this choice about the end of life, is a human right. Hannah appeared to have strong beliefs about this, feeling that assisted dying should be globally available;

"100, and how many 1 million extra percent you can add to 100%...I think it is a human right, and I cannot believe that w- every single person in the world, is not allowed to choose for themselves". (Hannah)

Which she connected to a belief about the right to hold individual control;

"Umm, somebody having that control over me, is wrong" (Hannah)

Mark, however, seemed to suggest that the right to choose an assisted death should be in more specific circumstances; permitted in specific medical contexts that induce unbearable, unrelievable suffering, similar to how we relieve intractable suffering in animals through euthanasia;

"Well I think there ought to be medical contexts…If they've got no quality of life then I, then I firmly believe that they have a choice, their choice, nobody else's, they have a choice of what to do. In this country they don't have a choice. They do over their little pet dog". (Mark)

Whereas Robert suggested there were emotional complexities surrounding his views on this, as a family member of someone who made that choice. He described holding general views about being *"pro-choice"*, but finding the emotional experience of his loved one executing this choice harder to reconcile;

"…in principle I would say, I'm…pro-choice…it should be an option for people to be in control of their own life…it's…a humane belief, almost…But there's a difference in principle, and you know how it affects you and how you feel about it". (Robert)

Finally, participants alluded to the current UK context posing restrictions on this right to choose, despite the option for UK citizens to utilise assisted dying services in Switzerland. It was suggested that the financial implications of this may prevent people feeling that an assisted death is a choice open to them.

Hannah identified that, although it appears that there is increased interest in being able to access an assisted death (as demonstrated by increased Dignitas membership), UK-membership numbers are still low, which she deemed to be related to the costs involved in going to Dignitas in Switzerland for an assisted death;

"British membership [of Dignitas]. It's gone up…in 2012, there were only 821. In December 22, there were 1,528, members…But I find that incredibly low, still…a lot of that, I suspect, is to do…with the financial aspect…you have to have a certain amount of money to be able to do this. So again, that is…not right, because it's restrictive". (Hannah)

Martin appeared to feel similarly; perceiving that for UK citizens, assisted dying is currently only an option exclusive to those who can afford it;

"…the ridiculous thing about it at the moment you know, t-to go to Dignitas is you know 12,000 pounds, something like that…yes almost like private medicine…isn't it". (Martin)

This suggests that participants see the current cost of assisted deaths as a significant barrier to those seeking one, impeding access to these services at the current time.

3.4.2 Ready for the end

A notion that people can be 'ready for the end' of life came across in a variety of the participants' accounts, with participants describing the belief that it is common for people to feel that they have *"had enough"* towards the end of life. For Hannah, this view appeared to be informed by engaging with her mother's friends in their older age;

"…it is just...common sense and kindness…to let people do what they want…my mother lived until she was 92. A lot of her friends…I've watched them all get tired…we have a finite energy…I've heard them all say, "I have had enough"…"I am just beyond tired. I want to go to sleep". (Hannah)

Whereas for Mark, this appeared to be informed by his concerns about living in a care home in later life, subsequently strongly believing that others currently in that situation would likely choose death if they felt that they had access to that option;

"…the last thing I would want to be is in a care home where they got me up s-and put me in a chair in a big room with one big television set there…And they're all sitting round it…No way. But there again those people are in there…because they haven't been given the opportunity...". (Mark)

For Robert, however, his beliefs that it is possible to feel 'ready' to die appear to come from a conversation he had with his wife, discussing the subjective meaning of a *"full life"* and her sense of having achieved that;

"…she was saying what's your…meaning of life, what's important to you in life…she was…saying that for her it was to live a full life, to love and to be loved [tears], to be a good friend to people, so I think she felt [tears] she'd done that". (Robert)

Whereas Martin's wife appeared to offer him the suggestion that this sense of being 'ready' might come from an acceptance that the path forward is not one that she wanted to continue on or would be fulfilled by. She told him;

"I have a diary which is full of social appointments, my friends ended up with a diary of clinical appointments" she said – what life is that?". (Martin)

Whilst these accounts offer various perspectives on the reasons why someone might feel ‘ready’ to die, they all seem to agree that it is possible to feel psychologically ‘ready’ for the end of life.

3.4.3 Duty to support the decision

A sense of duty to support their family members’ decision for an assisted death was another important theme across conversations. This appeared to connect with views around the ‘right to choose’ and benefits of individual autonomy, as well as being able to empathise with their family member questioning the quality and worth of continuing living, given their circumstances.

Hannah acknowledged accepting her mother’s choice, and appeared to feel quite content in supporting her in this decision;

“Yeah well, because it was for her…I only wanted for her what she wanted for herself. And we both knew what she wanted”. (Hannah)

Robert appeared to connect his sense of duty to support his wife, with the commitments he had made to her at their marriage;

“…before I was interviewed by the police I dug out our wedding vows…I think I said I would offer support, respect, compassion and understanding…I was guided; I was aware of the legal situation, that was what was important to me, to try and honor [tears] those vows…”. (Robert)

Despite this appearing to be at the cost of disregarding his own feelings, to be able to be a sounding board for her in decision-making;

“…I felt it was very important that, whatever my feelings were, that it was her decision [tears]. And, how much do you say to “what do you think?” “what do you feel?”…it was ultimately, whether she was influenced by things I said, it had to be, I mean it was her decision”. (Robert)

Martin, however, connected less overtly with the notion of ‘duty’ but described not being surprised by his wife’s decision, and feeling able to support it as it connected with views about what he’d want;

“…it didn’t surprise me that she chose that route…Oh absolutely on board with it…and I told her before that if I went before that’s the way I would choose to go”. (Martin)

Whereas Richard seemed to have felt surprised by his son's decision, but suggested that the *"big shock"* was quickly overridden by a strong sense of duty to support him however was needed;

"…we were all sat together and [Name] said he had something he wanted to say, which was that he wanted to depart this world. And…obviously it was a big shock…we both felt that he…needed to be supported in every single way possible…". (Richard)

These suggest that during decision making around an assisted death, family members prioritise the perspectives and choice of their loved one making the decision over their own needs or emotional reaction to this.

3.5 Navigating an "illegal" landscape

The need to navigate the illegality of assisted dying in the UK was prominent in the stories I heard from participants, but also in the challenges I experienced, and that participants alluded to, when talking together within this same landscape (see reflections in Chapter 4).

Participants reported frustrations about the limitations imposed on the interviews by the UK legal context and the Ethics Committee approving this study; with one participant sharing at the end of the interview;

"I've found it [the interview] difficult. I've found it difficult because you haven't allowed me to open up". (Mark)

It is possible that this sense of not being able to *"open up"* may have been connected with Mark's hopes for taking part in this research; perhaps wanting to share his story of his wife's assisted death, in contrast with the aims of the research being focused on hearing participants' perspectives on assisted dying. If such, it is possible that the interview experience may have replicated other experiences participants have described around feeling limited by the law in being able to openly share their experiences.

3.5.1 Being made to feel like a criminal

A sense of being made to feel like a criminal was a theme that transcended different participants' stories.

Hannah identified believing that family members are made to feel *"under hand"* during the assisted dying process, contributing adding pressure on both them and their loved one choosing an assisted death, during an already difficult time;

"…that is an added pressure on the person who has decided upon an assisted death, and anybody who…might know of those wishes…I think that is an added cruelty…everybody is made to feel under hand; "…I have to do this secretively, because if Fred Bloggs down the road, hears about it, and they don't agree with it, they can go and tell a policeman, and the policeman will come and knock on your door". (Hannah)

Whereas Mark appeared to have worried about whether friends would see him in this light given the current legal grey area in the UK, but feeling that any judgement regarding this choice should consider an individual's circumstances;

"…that it…you know technically, technically, umm you might be treading a bit close to the wind as they say… but having said that…I think you've got to relate it case by case…and, they'll change the law over here sooner or later – probably sooner". (Mark)

Robert seemed to feel that the legal situation meant it was difficult to access information about the process for accessing an assisted death in Switzerland from the UK, suggesting that this poses challenges to supporting a loved one with planning their death;

"…it is very difficult, because no organisations or groups will…really talk to you about it. They will explain what the legal situation is, and they may be a campaigning group who has a…belief that that the law ought to be changed. That's very different from anybody actually…providing information or…certainly advice…as soon as you get to the word advice, as opposed to information, then it becomes very tricky". (Robert)

He also acknowledged that, following his wife's death, he had been interviewed by the police; an ultimate example of feeling like a criminal, despite subsequently being cleared of any charges;

"I've been interviewed by the police, they're not going to take any action, I don't feel that I've done anything illegal". (Robert)

Robert's experience appeared to connect with Hannah's views that it is wrong that family members are made to feel this way, despite prosecutions being rare. She seemed to suggest that the legal grey area brings more distress than if the UK law had more clarity around this;

"…The gentleman had gone for an assisted death, and his wife did have the policemen knocking on the door…and was questioned when she was mourning her husband…that's not right…particularly when fortunately, there are no prosecutions…But it's still illegal. But

there hasn't been a prosecution…again, that's a nonsense…either send us all to prison for 50 years hard labour or don't…don't hang that over people…". (Hannah)

This theme also resonated with me as the researcher; I noticed that although working within the limits agreed with the Ethics Committee, I was constantly questioning whether I was doing anything 'wrong', even just when researching online about assisted dying for this report. This allowed me to sympathise with aspects of the participants' experiences.

3.5.2 Burden on healthcare professionals

As part of navigating this 'illegal' landscape, participants appeared to be aware of the challenges posed to UK-medical professionals of being seen to 'support' someone to have an assisted death. Hannah suggested that it was difficult to be transparent about the reason her mother needed access to her medical records, due to worries about implicating medical staff;

"…extraordinary getting medical records, getting various things, feeling like a…cheat. I'm putting on for this, and we mustn't quite say why all that is because everybody else will be scared that they've assisted her". (Hannah)

Whereas Martin identified that, when people do share their reasons for needing medical information, given the current context, he understands why medical professionals are so reluctant to help;

"I can understand that entirely, if they carry out a consultation with a person that is intending to have an assisted suicide, they're breaking the law really, or it could be construed as they're breaking the law, writing…a report, that allows him or her, to go off to Switzerland to have an assisted suicide…I think it's totally wrong. Giving a medical opinion for anything, shouldn't be wrong…". (Martin)

Robert appeared to agree with this, sharing an example of when this had caused problems for his wife's GP. He suggests that even though his wife's GP was continuing 'treatment as usual', knowing that her patient was planning an assisted death left her implicated;

"It was frustrating as the GP had done nothing other than providing medical information. And yes, she knew…so she was aware of what [Name] was planning, but…she would continue to be supportive you know, to any medical needs that [Name] had. But it sounds like the legal situation has put her in a difficult situation...". (Robert)

These accounts acknowledge the difficult position currently faced by medical professionals in the UK when caring for people who are considering an assisted death, noting that just being aware of this decision can have unwanted repercussions.

3.5.3 Sharing on a need-to-know basis

The current legal situation in the UK, and possible implications of this for those aware of the planned assisted death, appeared to influence some choices made about sharing their family members' wishes with others.

Richard seemed to believe that his son's choice to tell a limited number of people was due to worries about possible implications for anyone that knew, which was difficult to navigate within the family after his death;

"…[Name]'s grandma is a little more belligerent…about the fact that she hadn't been told…but it was very much [Name]'s wish that she wouldn't be told…[Name] was very anxious to protect all of us…that's why, you know, nobody was told". (Richard)

Whereas Mark reported that his wife chose not to tell the medical professionals involved in her care about her plans, unless it was necessary, which was also assumed to be related to possible implications of others' knowing;

"…she didn't tell the…carer until she got a date, and that was two weeks' before…She didn't tell the district nurses. She didn't tell anybody in the medical profession…the only one that she did tell is her doctor…There's certain things you have to do and procedures you have to do such as you have to supply the medical record". (Mark)

Others appeared to feel that choices to share were based on personal preference, rather than the legal situation. Robert described how he felt that his wife had chosen not to disclose her plans, as she didn't want to manage others' reactions to the news, or the impact it might have on relationships;

"…she tried it out with a, brother, and one or two close friends, and then decided that it was, complicated because she would have to deal with their emotional reaction…and it would affect that relationship from then on". (Robert)

Hannah described feeling that it was not in her mother's nature to want to widely share this, but also that there were few people who would be emotionally or practically affected by her mother's death;

"N-nobody else. Very small family…she was a very private person, and didn't discuss it with any of her friends…she didn't want to tell anybody". (Hannah)

Overall, whether influenced by the legal situation and/or personal factors, all participants noted that disclosing information about the assisted death was informed by their loved one's wishes on this;

"…if she wasn't telling anybody else then neither was I". (Mark)

This connects with the shared sense of duty to support their loved one, both in their decision for an assisted death and in the associated choices around this decision.

3.5.4 Support on this journey

When reflecting on the journey participants had been on, and given the barriers described around openness, consideration was given to what helped participants in navigating this journey. This brought mixed responses.

Robert identified that, because of the legal situation, the journey can feel isolating, and lack support, as it feels like there is no one who understands;

"I mean, [Name] did find a Facebook group in the end, which was primarily Americans…Canadians on it, where they were talking about assisted, dying…but there was nobody really in this country. You can't talk to you know, she couldn't talk to other people really, in similar situations, and I couldn't, there was nobody for me to talk to". (Robert)

But, since his wife passed away, he noticed benefitting from talking to others, which appeared to be an unexpected way of coping for him;

"…I've got quite used, in the past few months since [Name] died of a) thinking a lot and b) talking a lot in a way that…doesn't come naturally to me. But a lot of friends and family have spent a lot of time listening to me ramble on…and sometimes that rambling is…a process of me trying to understand what I'm feeling…". (Robert)

Mark seemed to feel that he needed to open up about his wife's death, and noticed the benefits when he did, despite having initial reservations due to concerns about what others might think;

"…you have a situation where you've really got to speak to somebody…In fact I was…quite surprised by…some of the guys' attitudes towards me…in the sense of, "really sorry to hear [Name]"…they were…very helpful". (Mark)

Hannah appeared to feel differently about talking with others, feeling that it is not something that she draws on generally;

"…I'm, I'm bit odd, I don't talk to people. No but I don't…how do you say? I hold my own council?... I don't need to talk stuff through with folks…I'm not a committee person. I'm not a counseling person…if I've made the decision. I've made the decision, and I live with my decisions…and I'm quite happy to do so". (Hannah)

Or something that was needed in this situation, due to the certainty that this is what her mother wanted;

"And I said, I'm actually fine, because I'm happy because she's happy". (Hannah)

Richard also suggested that he didn't feel the need to seek support from others during this time, particularly professional support, due to not perceiving it as necessary. He explained that since his son's death, maintaining life as usual had helped distract himself from the pain of his loss, and helped him to move forward;

"…in the last [time since death], actually having work to do is helpful coz it distracts you, it gets your mind off things…I'm not conscious of anything in particular that I've done or thought…that I've used to alleviate any sort of apprehensions or so…I've just got on with whatever I've had to get on with and done what I can…I haven't gone to any counsellors…I can't say that my life or my being or my bearing has changed in the slightest". (Richard)

Martin also noted that he had not considered seeking professional support during the assisted dying process or since his wife's death;

"…I haven't [sought professional support e.g., counselling etc.], you know, perhaps I should have done [laughs] I don't know. But it's now and er I think I'm a bit late". (Martin)

But shared the strategies he had used to cope following her death, which included maintaining an active social life and actively seeking out new hobbies. This appeared to be for the purpose of finding new companions in his life after losing his wife;

"…I had two close friends who are brilliant…I have a couple of drinks with them…two nights a week, we play games of cards and things like this…the normal sorts of things that old men do together…I joined classes…I did a course on creative writing and I've done history and I'm learning sign language at the moment…and part of this is because um they're pathways to more friendships…if you go to a class, you meet people, you interact, you get to know each other, you share a drink, um I've made a lot of friends". (Martin)

These extracts illustrate the range of unique ways that different family members may navigate and respond to the assisted death process and death of their loved one.

3.6 Assisted dying should be legalised

Across interviews, participants considered the current debate about whether assisted dying should be legalised in the UK, with the general consensus that it should be.

3.6.1 Assisted dying as part of modern medicine

Participants appeared to believe that assisted dying should be legal in the UK, as part of developments in *"modern"* medicine. The UK's current position appeared to leave Richard feeling *"resentful"* that his son had to go to Switzerland to access this service;

"…I feel resentful of…my government and…these medical profession…that we've…been put in this position…no I think just sorta resentful of the, that our laws aren't as modern as they are in other countries". (Richard)

When thinking about differing perspectives on the topic, despite no participants identifying as holding strong religious views, many alluded to the role of religion in the stigma around assisted dying. Robert appeared to feel that religious views might prevent some others from accepting assisted dying;

"…for some people with a specific religious belief they may believe in a specific afterlife or they may feel that you know, assisted death would be, yeah, morally wrong or...". (Robert)

Hannah appeared to agree; noting the possible complexities of assisted dying within religious belief systems. She appeared to be suggesting that her beliefs around the right to assisted dying are likely due to not holding religious beliefs;

"…people who believe…must be very…conflicted, because, if the Church that you believe in tells, you can or cannot do that or that's a sin, then you must really be in a…it must be much more difficult actually". (Hannah)

Whereas Mark appeared to suggest that the church, specifically, held some responsibility for the current *"out of date"* laws in the UK;

"My feelings are basically that we are totally out of date. Umm, and not only that, there are certain areas of the church that are particularly antigon-antagonistic against it". (Mark)

Despite the barriers, Hannah felt hopeful that the momentum of other countries legalising assisted dying might have an impact on UK laws;

"The more countries that do it in advance of us, the better the chances are of it happening in this country, but if not, I will get on a flaming plane…but all of that shouldn't be necessary". (Hannah)

3.6.2 Issues around misuse

All participants acknowledged the arguments often voiced against the legalisation of assisted dying, connected with concerns around the potential for misuse of these services. Mark appeared to suggest that there may be issues with assisted dying services in other countries, acknowledging that these services should not be used as a way out of social issues that have not been adequately addressed;

"I read that in Canada…they're finding that a lot of people out there, more than, well err, enough to be noted, have gone into it for poverty, because they can't afford to live. Now that's…not on". (Mark)

However, Hannah, when considering the concerns around the possibilities for coercion, felt that the likelihood of this was limited and didn't outweigh the demand for assisted deaths;

"I understand…there might be… somebody, and you're loaded, and they could steal your money. "You'll sign this, auntie so and so sign this"… If that's one person out of… a million, you know, that's got a crooked relative… then in my opinion, I'm afraid that one person has to go…that minority of, of potential accidents… cannot be allowed to overrule a majority, because it's now a majority of people who want to have the choice". (Hannah)

Others seemed to feel that it is possible for these risks to be adequately managed so that these services can be available to those who might benefit from them. Martin appeared to feel that Dignitas' current policies around assessing decision-making capacity are acceptable for this;

"Well again, Dignitas cover that don't they with their need for a Psychiatrist's report and I think, yes, people who have mental health, and also there is coercion, you don't, people who are in the throws of early dementia and stuff like that may not be able to make a decision properly themselves, um so if you have dementia you have to get in there quick don't you". (Martin)

It was also felt that, should assisted dying become legal in the UK, there could also be sufficient protections put in place to sufficiently manage these concerns;

"…I agree with it [assisted dying] in principle and yes, it is difficult and there's huge questions but…that doesn't mean that we shouldn't…make even larger efforts to try and address the issue, and put something in place that um does provide the appropriate protections". (Robert)

"…I don't see any problem as being unsolvable, I can see them being contentious but um, I feel that all of these problems if properly discussed and properly investigated can be overcome and the law framed around it, to allow people like me to say "right I've had enough". (Martin)

Chapter 4: Discussion

4.1 Chapter overview

This chapter will summarise the main findings from this study associated with the research aims. The results will be contextualised within the current UK and global landscape of assisted dying, and connected to existing literature. The study's strengths and limitations with be considered, alongside the implications of the findings and suggestions for future research.

4.2 Summary of findings

This study aimed to explore the perspectives on assisted dying of UK-based family members of someone that has had an assisted death. It was also interested in the contextual factors that informed these perspectives, how these perspectives might fit with family members' prior views on death and dying, and the resources family members draw on when supporting a loved one on their journey to an assisted death, and afterwards.

To investigate these research questions, data was collected by interviewing five participants and analysed using IPA. The analysis identified four themes; A life dictated by illness, Life as autonomous, Navigating an "illegal landscape", and Assisted dying should be legalised each with a number of subthemes (see section 3.2). The study's findings will now be considered in relation to each of the research questions.

4.2.1 Perspectives on assisted dying

Overall, participants appeared to view assisted dying as being an important option in medical care; whether this be for relieving current 'unbearable' suffering (Dees et al., 2010), preventing future unbearable suffering, or for other reasons such as feeling 'ready' to die. It was emphasised that people should have the right to choose to end or prevent unbearable suffering, connected with the importance of having a quality of life (in whatever way this means to them), not just existing. This right to choose, even in contexts where unbearable suffering is inevitable but not present currently, connects with the wider literature that acknowledges that family members feel that the right to choose offers individuals an opportunity to feel that they have some control or agency over their life direction. This can be important at a time when it feels that this is lost to a medical diagnosis (Holmes et al., 2018; Laperle et al., 2022; Srinivasan, 2019; Thangarasa et al., 2022).

For some participants, these perspectives appeared to connect with longstanding views around the importance of autonomy and choice, and their experience of supporting their loved one had only cemented their views. For others, supporting their loved one had required them to consider their views on assisted dying, which had previously been less considered, or based more generally on life principles (e.g., being pro-choice). These participants identified that the experience of supporting their loved one had been pivotal in making sense of the meaning of an assisted death and seeing the benefits to having this option, despite the emotional complexities it can bring. Seeing the benefits after supporting someone through the process, connects with the findings of the SLR on ‘challenging belief systems’: despite initial reservations, ultimately family members often feel that an assisted death was the right decision for their loved one and their situation (Beuthin et al., 2022; Brown et al., 2022; Gamondi et al., 2015; 2018; Holmes et al., 2018; Srinivasan, 2019). Participants additionally shared concerns that the current laws in the UK are withholding this right to choose from many, due to the financial implications of being expected to go to Switzerland, despite views that others might choose an assisted death if it felt like a viable option. Issues were also highlighted around the stigma associated with assisted dying being illegal and the lack of information and support with the process from the UK, which may also contribute to others not currently feeling it is an option open to them.

Participants also all acknowledged the concerns often documented in the media around the misuse of assisted dying services. This is not something that came up in the SLR when assessing views of family members globally. Participants generally agreed that any legislation for the legalisation of assisted dying in the UK must include sufficient safeguarding strategies to mitigate for misuse, but felt that appropriate resolutions to these concerns were possible so that services could be accessible to those that would benefit from them. Despite highlighting these areas of concern, participants all indicated that they would support a change in law in the UK, and that they expect that this is likely in the near future.

4.2.2 Contextual factors

Participants situated their perspectives about assisted dying within examples of their experience of supporting their loved one during unbearable suffering and/or on their journey to an assisted death, at a time when assisted dying is illegal in the UK.

Participants' perspectives appeared to be mainly influenced by witnessing the unbearable suffering, or expecting their loved one to experience unbearable suffering in the future, alongside feeling the impacts of their loved ones' situation on their lives. These contextual factors appear to contribute to a strong sense across participants, that in some cases, choosing death is the only way to relieve experienced or inevitable unbearable suffering resulting from particular medical diagnoses. This supports the wider literature in seeing assisted dying as a means of preventing human unbearable suffering (Gamondi et al., 2018; Hales et al., 2019; Holmes et al., 2018; Snijdewind, 2022; Srinivasan, 2019). It also suggests that in a certain contexts, family members view death as being a therapeutic goal (Masel, 2022). Furthermore, similar to the notion of 'co-runner' (Thangarasa et al., 2022), participants all reported feeling significantly involved in conversations around their loved ones' decision to have an assisted death, which appeared to leave them closely aligned to their loved ones' experiences and beliefs that culminated in this decision.

Participants all reported to not hold religious beliefs, with a general sense that religious beliefs may pose possible barriers to others being accepting of this mode of death. Participants, however, all appeared to hold strong beliefs around individual autonomy, and the need for this to be privileged in healthcare and decision making around unbearable suffering and/or end of life care. This connects with autonomy being something that is privileged in western approaches to healthcare (Goldberg et al., 2021). In line with privileging individual autonomy, it is therefore not surprising that participants felt a duty to support their loved ones' decision for an assisted death, given the demographics of participants and western context in which this research is situated.

Participants readily shared their experiences and the perceived impacts of both navigating the practical challenges that were faced on this journey, as well as the challenges associated with assisted dying being perceived as a stigmatised death. This appeared to question participants' perspectives that assisted deaths are not 'wrong', as they were needing to act in a way that suggested they are. However, these experiences are not surprising, given that it was identified in the global literature, that even in countries where assisted dying is legal, it is still stigmatised, which can result in family members feeling the need for secrecy around the mode of their loved ones' death (Brown et al., 2022; Gamondi et al., 2015; 2020; Hales et al., 2019; Srinivasan, 2019). However, participants in this study also acknowledged that despite these perceptions, when they had opened up to close others (perhaps scoping their perspectives prior to doing so), they had received the support they wanted.

It was also identified that, due to the legal context, and concerns about possible legal implications, family members were selective about who they chose to disclose the planned assisted death to, and that this mode of death resulted in very few people coming together. This is in contrast to the reports in the literature, suggesting that assisted dying offers families the benefits of coming together during this period (e.g., Gamondi et al., 2018; Holmes et al., 2018) for ending rituals (Buchbinder et al., 2018; Gamondi et al., 2018; Holmes et al., 2018). However, participants did identify the benefit of being on the journey with their loved one in preparing for the end, which although in a more limited capacity than described in the literature (e.g., Beuthin et al., 2022; Holmes et al., 2018; Srinivasan, 2019; Thangarasa et al., 2022), highlights the importance of being able to work towards this goal together. The legal context in the UK alongside stigma around assisted dying appear to contribute to choices around the limited involvement of others and possible implications of this.

4.2.3 Prior views on death and dying

This study also gathered general views about death, and dying. Participants connected their views around life and life choices, and subsequently death, around upholding individual autonomy. This appeared to be connected with longstanding views associated with privileging choice and the right not to live with unbearable suffering, due to constraints to perceived quality of life. This connects with wider literature acknowledging that assisted deaths end unbearable suffering (e.g., Gamondi et al. 2018; Hales et al., 2019; Holmes et al., 2018; Snijdewind, 2022; Srinivasan, 2019).

Participants who had been in caring roles readily shared their experiences of the constraints of caring for a loved one, and despite acknowledging they were doing it out of love for their partner, and feeling less constrained than their partner, they had noticed significant impacts on their own quality of life. This connects with the literature which acknowledges the significant role that family members play in care (Goldberg et al., 2021) and the impacts that medical diagnoses can have on families as well as the individual (Cheung & Hocking, 2004; Eriksson & Svedlund, 2006; Gamondi et al., 2018; Patterson & Garwick, 1994). Others appeared to hold more longstanding negative beliefs associated with being cared for by others (e.g., not wanting to be a ‘burden’), which may have influenced their views around assisted dying, and dying more generally, in addition to knowing their family members’ reasoning for making this choice. This appeared to influence their beliefs that assisted dying has a role in medical care, as it was felt that, being in a position of needing to rely on others for all aspects of life functioning, and lacking independence, may, for some, constitute unbearable suffering and subsequently lead to the desire for an assisted death.

Participants also identified beliefs that, for a multitude of reasons, people might feel ‘ready’ for life to end (e.g., a sense of having lived a ‘full’ life, acceptance that the path forward is not what they want or the exhaustion of older age and therefore waiting to die). These appeared to connect participants with feeling that people should have the right to choose when life ends, rather than this being dictated by those in charge of their medical care. This aligns with Masel (2022)’s questions around whether medical care should focus on preserving life (as per the current focus in the NHS to mitigate suicide; Department of Health and Social Care, 2019; NHS, 2019) or privilege patient autonomy, particularly in contexts where death can end longstanding unbearable suffering.

4.2.4 Resources

Beliefs around individual autonomy also appeared to inform the coping mechanisms participants used during this period. Participants seemed to prioritise their sense of duty to support their family member, deeming their own emotional response or needs during this time as less important. Some participants described finding talking with others beneficial, whilst others didn’t feel the need and/or weren’t able to talk to others, except the person having the assisted death. Participants recognised that talking with the person choosing an assisted death and being on the journey together had felt supportive, but it was acknowledged that it was then harder continuing on the journey alone after their death. As a result, one participant in particular had made active decisions following his wife’s death to continue engaging in regular activities with friends, alongside taking up new hobbies as a way of building new connections.

All participants had not considered professional support (e.g., talking therapies) before and/or after their family members’ death. This did not appear to be related to the legal situation in the UK, but more with individual styles of coping. However, participants who had wanted to, or chosen to, talk to others in their circles had noticed that at times this came with challenges due to perceived stigma and the legal context. Questioning others’ beliefs about assisted dying and the impact of them sharing their family members' choice, as well as their felt vulnerability to possible police investigation if they were seen to have 'assisted' the death in any way, both appeared to pose barriers for talking. This seemed to often lead to talking with others being on a 'need to know' basis for practical reasons, rather than for emotional support, despite the literature identifying the benefits of families coming together during this time (e.g., Gamondi et al., 2018; Holmes et al., 2018). It is also noted that the one participant in this study who benefitted from offloading to others following his wife's assisted death reported to have already undergone a police investigation and been 'cleared' of any possible offences. This may have aided him feeling able to talk with others more freely. This connects with current literature identifying the perceived stigma associated with assisted dying, and the obstacles this poses for being open with others, even in contexts where assisted dying is legal (Brown et al., 2022; Gamondi et al., 2015; 2020; Hales et al., 2019; Srinivasan, 2019). This suggests that the added layer of the illegal status of assisted dying in the UK contributes further burden to these conversations.

Whilst participants hadn't considered services such as talking therapies for other reasons, it was suggested that accessing guidance or advice about the assisted death process could have been useful ahead of the assisted death, but wasn't possible given the legal status. This appeared to pose barriers to accessing the assisted death itself (e.g., impeding access to medical documentation to share with Dignitas), as well as concerns about implicating medical professionals. This was deemed to be problematic, suggesting that accessing medical support and making choices around medical care should not be prevented. These findings add novel understandings of family members' experiences of assisted dying to the literature.

Overall, a sense of just 'getting on' with things as a way of coping emerged through these conversations, whether this be as a distraction from the sadness of the loss of their loved one, or a sense of not feeling the 'need' to grieve, given the comfort felt in believing that their family member had made the right choice for them. Given the demographics of the participants (see section 2.3.4), these beliefs may be related to generational and/or cultural beliefs around accessing help and coping (e.g., the importance of independence and not relying on others). It is also possible, as the current literature suggests, that the nature of the death being planned and chosen offers closure for family members, through the ability to plan the death together, engage in ending rituals and knowing it is what the individual wanted (e.g., Gamondi et al., 2018; Holmes et al., 2018). This suggests that assisted dying offers family members the opportunity for ‘anticipated grief’ (Laperle et al., 2022), whilst the grieved person is still alive to support them in this process.

4.3 Reflections

Reflecting back over the experience of conducting this research, I am connected with my ‘other’ researcher position (Heath, 2018; Herod, 1999). I am conscious that my interpretations of participants’ stories may be influenced by my personal and professional circumstances that drew me to this research (e.g., my interpretations of unbearable suffering from my clinical experience, and my understandings of why people I know of have chosen assisted deaths; see sections 1.2 and 1.3). I note that my clinical experience specifically led to me being drawn to particular stories in the interviews and may have influenced what I gave more space for, pulled me to conduct interviews in a more ‘therapeutic’ manner, and/or influenced interpretations of the data I collected (e.g., wanting to ensure that the contextual factors were well understood).

When thinking about my relationship to the participants, I’ve connected with our similarities in Social GRRRAAACCEEESSS (Burnham, 2018), such as perceived class and race, as well as differences (e.g., age). I also noted similarities in some beliefs shared (e.g., around the importance of choice) and how this may have influenced what I privileged in my sense making of their accounts. During interviews, I noted that participants often made comments suggesting that I might ‘get’ what they meant; perhaps due to perceived similarities between us. Whilst this may have benefitted participants feeling more comfortable talking with me, it may also have meant that I didn't always explore aspects of their stories further, missing opportunities for more in-depth understandings of their experiences.

Finally, I want to acknowledge the emotional toll taken in conducting research on the topic of unbearable suffering, death, and dying. I note the emotional exhaustion I felt after each interview, and the reflecting and sense making I have continuously been undertaking around my personal beliefs on these concepts and where assisted dying might fit into these. I have made use of supervision, loved ones, and my reflective journal to work to separate these as much as is possible. However, inevitably, qualitative research is about collaborative meaning making and the joining of understandings and, therefore, it is also hoped that taking a critical realist lens for this research, alongside transparency about my changing position, offers an understanding that this research must be viewed with these in mind. Nevertheless, the feedback received from participants (see section 2.4.2) suggests that this research has adequately captured what some had hoped I would hear from their accounts.

I have also reflected on the possible differing reasons participants may have had for taking part in this research (e.g., for their story to be heard, feeling that their family member would have wanted them to take part, or that this research may inform the legalisation of assisted dying in the UK) and the impacts that these may have had on what was shared, located in this time in history. It is hoped that the theoretical orientations underpinning IPA have accounted for this; particularly that the meaning made from experiences is temporal and perspectival (Draucker, 1999; Orbanic, 1999; Small, 2017).

4.4 Implications and recommendations

4.4.1 Clinical implications

This study highlights the significant involvement that family members play in supporting their loved one through the decision-making process and on the journey towards an assisted death, even when it is illegal. This supports wider literature acknowledging family member support (Fujioka et al., 2018; Kimsma & van Leeuwen, 2007), and the importance of relational influences on the assisted dying process (Variath et al., 2020).

In the context of end of life planning, and/or when individuals are being given medical diagnoses where care/treatment/symptoms are expected to have a significant impact on an individual's life, care planning should, wherever possible, include family members. This study questions the notion that family members *need* professional support (i.e., talking therapies) during end of life/care planning (Goldberg et al., 2021). It also highlights the important role that family members play in negotiating the process to an assisted death and, therefore, the importance of family members being able to access guidance as appropriate (and dependant on the future legal context in the UK).

As Clinical Psychologists, particularly working in health contexts, this study highlights the importance of understanding the concept of 'unbearable' suffering (Dees et al., 2010) and its individual nature, in order to consider the best ways to support individuals and their families. It emphasises the importance of asking what families might need from us, and subsequently offering tailored support, rather than making assumptions about what might be helpful.

4.4.2 Policy implications

Given the significant role that family members appear to play in supporting their loved one on their journey to an assisted death, they should be better accounted for in relevant policy planning. This supports calls from the wider literature (e.g., Brooks, 2019; Council of Canadian Academies, 2018; Elmore et al., 2018; Fujioka et al., 2018; Roest et al., 2019) and is an important consideration as the UK continues to debate whether assisted dying should be legalised. This study suggests that the UK government would benefit from consulting with family members as part of this process, given that they have navigated the current system and therefore hold valuable expertise on this topic. Furthermore, given the perspectives shared around the possible impacts of religious beliefs on views around assisted dying, this suggests that the government would also benefit from consulting with a range of groups connected with different belief systems within the population (e.g., different religious, spiritual and cultural groups) to ensure to capture the possible range of perspectives within the UK. It is understood that this is an intention of the current public inquiry being undertaken by the UK government (UK Parliament, 2022b).

Should assisted dying be legalised in the UK, there is a need to develop clear policies for medical professionals around offering individuals who are considering or have chosen an assisted death and their families appropriate guidance about the process. This study suggests that this would benefit the individual and their family in feeling better supported and informed during the process. These policies would also allow medical professionals to have clear protocols to follow as part of their duty of care, and work to alleviate worries around possible professional implications of supporting this end of life choice. Additionally, concerns around the potential for misuse of services must be carefully considered, and stringent policies developed, to ensure that adequate safeguards are in place to protect those vulnerable to these services being misused.

Finally, the identified stigma associated with assisted dying indicates the importance of disseminating accurate information about this option in medical care and associated policies, should the UK continue to consider legalisation. This information could include clarity around the reasons why people might choose an assisted death, the stringent processes involved in accessing these services and the safeguarding procedures implemented to prevent misuse (Emanuel et al., 2016; Government of Netherlands, n.d; Mroz et al., 2021). Given the importance of choice identified in this study; access to this information would allow members of the UK population to be able to make more informed choices about their medical care and/or end of life.

4.5 Critical evaluation

This study is believed to be the first UK-based study considering family members' perspectives on assisted dying, contributing to the knowledge base of an emerging field within medical and psychological landscapes. Importantly, it offers perspectives on how the current systems for accessing assisted dying are working for individuals and their families living in the UK. Suggestions are also made regarding areas of consideration whilst the UK continues to debate whether it should legalise assisted dying. It is important, however, to hold this study's findings within the context of its strengths and limitations.

4.5.1 Study sample

This study met its hopes of capturing some differing relationships to the person that died. However, given the small sample size, and that all participants were recruited from the assisted dying organisation, Dignitas, there are limits to the generalisability of findings for a number of reasons. Firstly, it is assumed that individuals on Dignitas' mailing list are likely to be pro-assisted dying, and therefore the study's results may be skewed to those in support of assisted dying, missing other perspectives. However, it is also possible that being pro-assisted dying and holding beliefs that the UK may legalise assisted dying soon, allowed these individuals to feel comfortable taking part in this research within the current context.

Furthermore, all participants identified as feeling included in the decision making around their family member's decision for an assisted death, and therefore this study may not be generalisable to those who felt excluded from this process. It is identified that this may be due to the nature of the sampling strategies used, and the known biases around people who choose to take part in research.

It is also recognised that other recruitment channels for this study, which may have offered opportunities to hear a wider range of perspectives, were not fruitful and therefore these perspectives may not be representative of all family members in the UK whose loved one has had an assisted death. More consideration regarding how to make use of other recruitment channels (e.g., campaign organisations on both sides of the argument and/or recruiting people before the person has died) may be worthwhile to address the bias in recruiting from Dignitas membership for future research. However it is recognised that due to the current legal context in the UK, possible options for recruitment channels to studies like these are limited.

Importantly, it is acknowledged that these findings are based on a small homogenous sample with little diversity around ethnicity (responses were interpreted as versions of the category ‘White British’), family system (participants spoke about being part of small family systems), religion (participants identified as not holding religious beliefs) and socialisation to models of health and healthcare (participants appeared to ascribe to western models of healthcare). Therefore, whilst the demographics of participants do appear to be representative of the majority of individuals who currently access assisted deaths globally (Emanuel et al., 2016; Steck et al., 2013), these results are unlikely to be generalisable to different ethnic, cultural, or religious groups within the UK who may have different family structures, practices and/or belief systems. As such, caution should be exercised when considering how the results of this study are framed and utilised within health care systems and planning in the UK.

4.5.2 Recruitment criteria

Given that there is no current UK-based research on this topic, and the significant challenges recruiting to the project, the recruitment criteria were expanded to include family members up to five years after the assisted death of their loved one. Whilst the wide range of time since death may be perceived to be an issue in relation to homogeneity of the sample, this did not appear to contribute to any significant differences in the overall content of what was shared. However, it was noted that the ‘rawness’ of emotion was more present in interviews in which the death was more recent.

It is recognised that this expanded timeframe led to the inclusion of participants whose loved ones had died pre- and post- the peak of the Covid-19 pandemic, and the disparity in experiences and contexts this may have brought. Despite this, however, and the noted disproportionate impacts on those with caring needs (UK Parliament, 2022a), only one participant spoke to these possible impacts on his wife's suffering and the implications of lockdown on accessing external support. This suggests that others did not perceive their and/or their family members' situation in relation to assisted dying to be significantly impacted by the pandemic.

Despite its aims, this study also didn't include anyone identifying as a family member that was not either biologically related to the individual who had the assisted death, or related by marriage. It is unclear whether this is due to the recruitment materials not clarifying the breadth of the definition 'family member' for this study, or whether cultural understandings of the term 'family member' within this population are generally limited to these contexts. However, given that this is the first study of its kind, it was able to meet its aims of hearing UK-based family members' perspectives on assisted dying from some different family members. It also gathered valuable information that can inform decision making about legalisation in the UK, clinical decision making (e.g., around offers of support), and suggests recommendations for foci of future research (see section 4.6).

4.5.3 The limitations of the legal context

To my knowledge, this is the first study of its type, conducted in a country where assisted dying is not legal, and it feels important to acknowledge that this posed major barriers to all aspects of conducting this research.

Firstly, the legal situation may have contributed to recruitment challenges in a number of ways. My experience of connecting with campaigning organisations for support with recruitment was that organisations felt a strong need to protect their members, posing barriers to clear recruitment channels or conversations when designing and recruiting for this study. This meant that the 'scoping' and 'gatekeeping' stages of this project took much longer than hoped, which was challenging, particularly given the restricted timeframes of conducting this research within the limits of the DClinPsy. Furthermore, the legal context may have impacted whether some individuals chose to take part in this research, or even whether they made contact with me for further information, as by making this contact, they may have felt they were implicating themselves (e.g., by sharing personal details such as a name and email address). This may have been the reason that other recruitment channels outside of Dignitas were not fruitful, as the Dignitas 'stamp of approval' may have aided some individuals to feel safer contacting me.

Secondly, the legal situation, and in particular the resulting restrictions imposed on this study by the Ethics Committee, had an impact on the interview experience for participants and for me, as the researcher. For me, needing to identify the limits of the interview in relation to the law, and the guidelines from the Ethics Committee, at the start of the interview felt at odds with my strive to help participants feel comfortable talking with me, particularly given we were talking about the loss of their loved one. Furthermore, the need to follow the disclosure protocol agreed with the Ethics Committee meant that I, as the researcher, felt on edge during interviews, feeling a sense of responsibility to ensure that participants didn't share any information that might implicate them, or me, in this process. This made it difficult to 'relax' into conversation together, or to explore aspects of the participants' stories that may have offered a richer understanding of their perspectives. The impacts of this were particularly acknowledged by one participant in their interview (see section 3.5).

Finally, as a researcher I have felt a strong need to protect participants involved in this research from any possible legal implications of taking part, and a simultaneous frustration that I have not felt able to conduct this research more freely, particularly given the limited prosecutions in the UK, and the perceived move towards legalisation (Crown Prosecution Service, 2014; Hurford, 2020). I feel that the stigma identified by participants, and in the wider literature around assisted dying, may have impacted decisions made about the boundaries of this research. I hope that, as more research about assisted dying is conducted, there may be opportunities to undertake this important work more freely, to inevitably gather richer data and better understand this topic.

4.6 Possibilities for future research

This study explored UK-based family members' perspectives on assisted dying and identified a range of associated factors (e.g., witnessing unbearable suffering, constraints of offering care and views around the importance of autonomy and choice). Of these, participants spoke to how contextual factors informed their perspectives, particularly how these factors influenced their family members' decision and were informed by family and/or cultural factors. Future research could explore these further; particularly considering the role of these factors and attempting to recruit participants from a variety of backgrounds.

Given the perspectives shared around quality of life being an important factor in decision making, studies may also want to explore different understandings of quality of life and what may be deemed 'poor enough' quality of life to warrant an assisted death. Studies could also explore different support options for individuals and their families at times of unbearable suffering and/or end of life in relation to specific belief systems (e.g., the possible role of religious figures offering support during times of unbearable suffering and/or when an assisted death is being considered). It may also be useful to explore other perceived barriers to seeking assisted deaths at these times, aside from financial implications and legal constraints.

Finally, this research identifies the need to better understand the perspectives of those impacted by seeking an assisted death in countries where it is not legal. As such, future research on this topic may also benefit from speaking to those in these contexts (e.g., the UK), who are considering an assisted death for themselves.

4.7 Conclusions

This study explored the perspectives of UK-based family members of people who have had an assisted death, on assisted dying. This is the first study of its kind both in speaking to family members in a country where assisted dying is not legal, and hearing UK-based family members' perspectives. This study offered the opportunity to gain an understanding of these experiences and perspectives, at a particularly challenging time in the UK; navigating a complex legal grey area around the implications of supporting a loved one to an assisted death.

The findings illustrate that UK-based family members believe that there is a place for assisted dying as offering an end to unbearable suffering, preventing anticipated future unbearable suffering, or because someone feels 'ready' to die. This suggests that family members who have lived experience of supporting a loved one with this choice, can see the benefits of individuals having choice about death in these contexts, and are supportive of this, despite navigating their own relationship to losing their loved one. The findings also suggest that there are individual differences in how family members navigate this period and therefore the different possible support needs they may have. For this reason, any services offering support should ask family members what they might want/need during this period, rather than making assumptions about support or working in a 'one size fits all' approach. This study also highlights that, despite the legal status, family members in the UK, similar to those globally, feel involved in the assisted dying process of their loved one. They are therefore important stakeholders to consider in policy development, both associated with possible legislation, should the UK choose to legalise assisted dying, and/or in relation to support services being offered to people and their families who choose an assisted death.

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6 Appendices

Appendix A: Extracts from research diary

Reflective diary extract 1: Criteria for SLR

I’ve been thinking about the focus for my SLR.

After lots of thinking, I think the most useful thing would be to understand views of family members within the global literature as think this funnels best into my research and will help me consider what I can expect / what I might need to ask about and offer some comparison for my results too. But it’s making me think how specific am I going to be with eligibility criteria for the SLR? Can this be views of all family members (i.e. including family members of someone considering an AD) or do I want to keep it specific to the focus of my project (e.g. only family members after the AD)?

It feels like the difference between principles versus lived experience is important here. I keep thinking how it can be possible to have strong principles (beliefs?) about something but then when it comes to experiencing that thing it might feel very different (people often talk about that in relation to experiences / choices around having children).

Family members’ beliefs without the experience could be valuable, but I’m not sure they will be as helpful in informing this study? I think it’s important to only include family members whose loved one has had an AD so that their views are grounded in their experience.

Reflective diary extract 2: Dilemma around experts by experience for this project

One of the campaign organisations has just told me that they can't help me with possible EbEs as I don't have ethics yet. It makes sense, particularly given the legal situation in the UK – I get that they are wanting to protect their members. I'm just feeling a bit stuck about how to navigate this as I do feel that I need and want EbE expertise in designing this study.

It's making me think; should I ask the people I know? Or is that too close to home?
I've been thinking about what an EbE is, in relation to research, what I'm asking of them – would they feel able to say no to me given they know me, if I asked if they want to be involved? Would they feel able to critique my work? Or would they feel that they had to tell me I'm doing a great job? Does it matter that they aren't based in the UK? Would I feel able to maintain some sort of boundaries around the role with them? I do think so…

I think they'd offer me some really valuable perspectives about what it's like being a family member of someone that chooses, and then has, an assisted death, which is something I think I'd really benefit hearing about to ground myself in the context for this project. I keep feeling like I don't really 'get it' (I guess my outsider researcher position) and think conversations with them, maybe because I know them, perhaps I will be able to connect more with what they're sharing? I also think I'd have some really great conversations with them, and it would be nice to reconnect too.

I know they aren't based in the UK and assisted deaths are legal over there but this definitely seems like a good starting point. I just think if I speak to them I will really need to make it clear that they don't have to be involved at all, but if they do want to it can be as much or as little as they like.

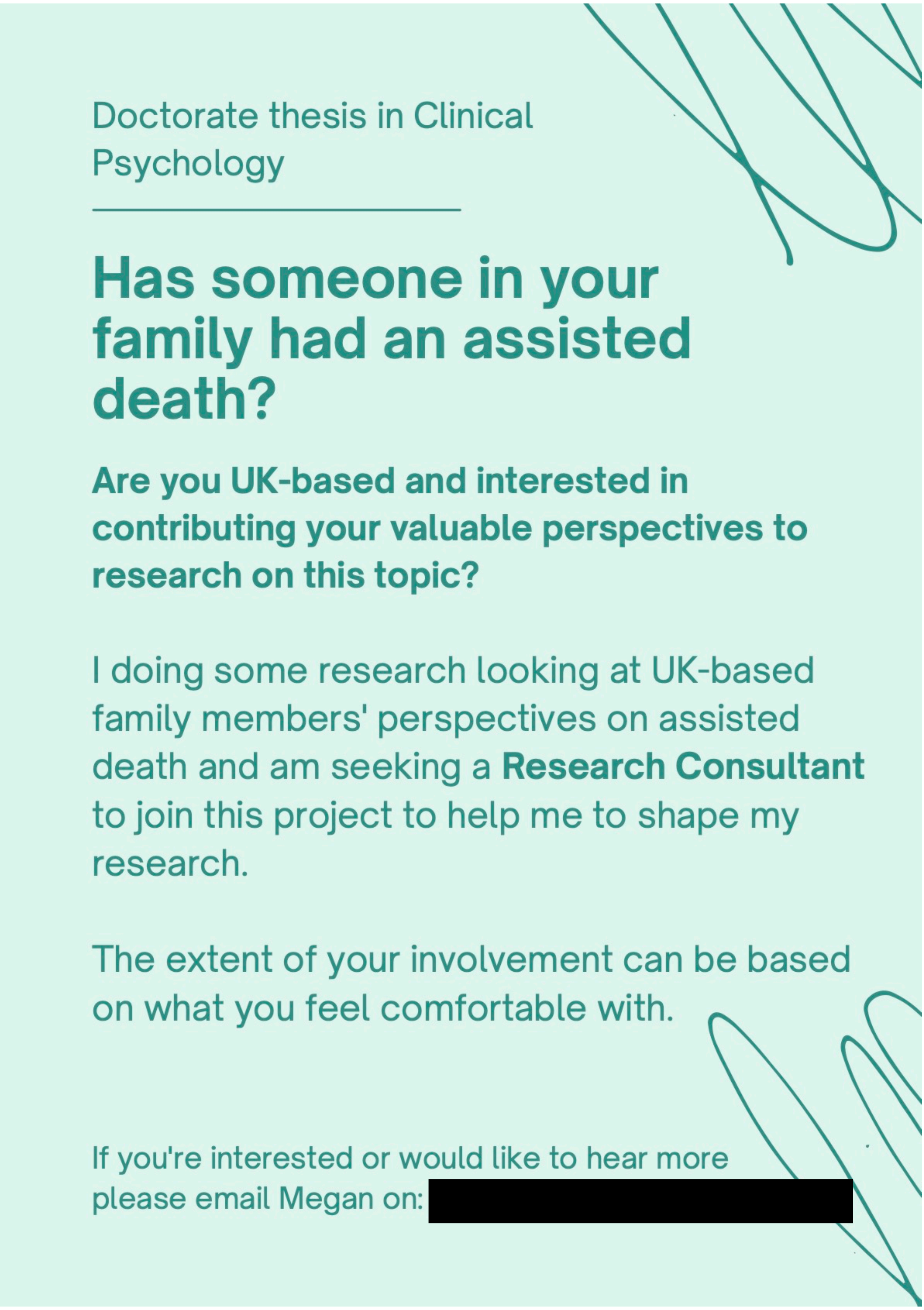
Reflective diary extract 3: Reflections on issues around offering participant choice for interview modality

I've just had contact with a participant who lives quite far from where I live and I'm not sure what their preference will be for having the interview but I feel like I'm in a dilemma. When designing this study, I felt strongly about offering options for interview for how participants wanted to be interviewed (F2F v Zoom etc) – it just felt like it made sense. I really wanted participants to feel as comfortable as possible being involved in my research - particularly given that I was asking them questions about losing a loved one. Also after talking with one of the EbEs, I thought lots about how to help participants feel that they can trust me in the current legal context – including getting the research phone so I am not calling on a private number… I also assumed some might want to meet me F2F to help with feeling they can trust me.

But now this does not feel as straight forward! I'm not sure I will have time to travel potentially anywhere within the UK if a participant wants me to. I really should have thought about this and put a caveat to this in my information sheet – something like "wherever practical and possible, participant preference will be honoured". But then ethically, it doesn't feel right to privilege people living near me for interviews - but then practically, given DClinPsy time restraints that just might have to be the case?

I think this will need to depend case by case and also when participants are recruited and what else is going on for me at that time – but I will probably have to say if they are based too far away from me (?over a couple of hours drive) that practically I will need to conduct these interviews on Zoom or over the phone? This is definitely something for me to consider for doing research in the future – definitely making me think about 'ideal' standards within research but then practical barriers when actually conducting the research.

Appendix B: Expert by experience recruitment poster



Doctorate thesis in Clinical Psychology

Has someone in your family had an assisted death?

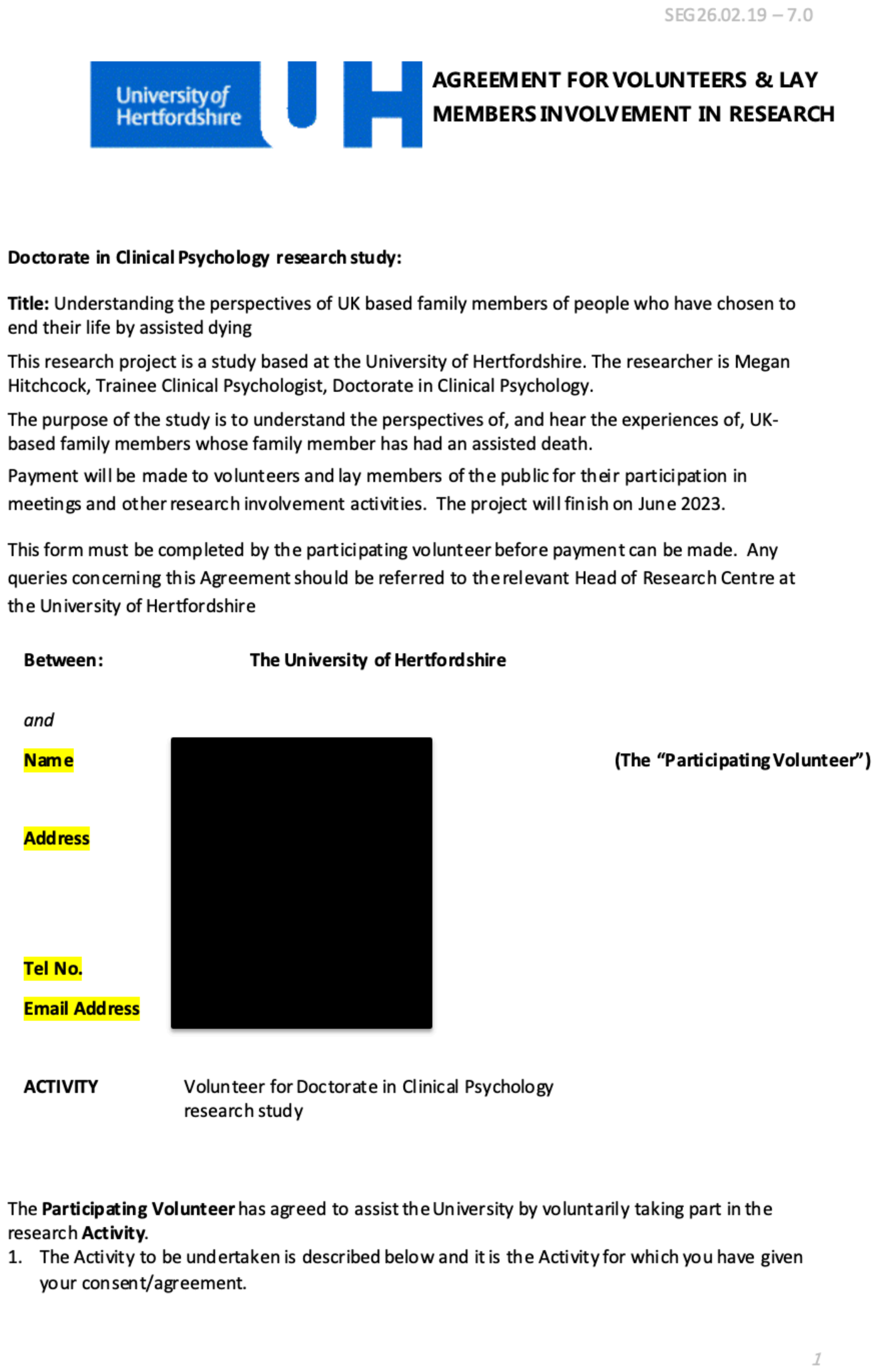
Are you UK-based and interested in contributing your valuable perspectives to research on this topic?

I doing some research looking at UK-based family members' perspectives on assisted death and am seeking a **Research Consultant** to join this project to help me to shape my research.

The extent of your involvement can be based on what you feel comfortable with.

If you're interested or would like to hear more please email Megan on: [redacted]

Appendix C: ‘Agreement for volunteers & lay members involvement in research’ form



SEG26.02.19 – 7.0

University of Hertfordshire UH

AGREEMENT FOR VOLUNTEERS & LAY MEMBERS INVOLVEMENT IN RESEARCH

Doctorate in Clinical Psychology research study:

Title: Understanding the perspectives of UK based family members of people who have chosen to end their life by assisted dying

This research project is a study based at the University of Hertfordshire. The researcher is Megan Hitchcock, Trainee Clinical Psychologist, Doctorate in Clinical Psychology.

The purpose of the study is to understand the perspectives of, and hear the experiences of, UK-based family members whose family member has had an assisted death.

Payment will be made to volunteers and lay members of the public for their participation in meetings and other research involvement activities. The project will finish on June 2023.

This form must be completed by the participating volunteer before payment can be made. Any queries concerning this Agreement should be referred to the relevant Head of Research Centre at the University of Hertfordshire

Between: **The University of Hertfordshire**

and

Name [redacted] **(The “Participating Volunteer”)**

Address

Tel No.

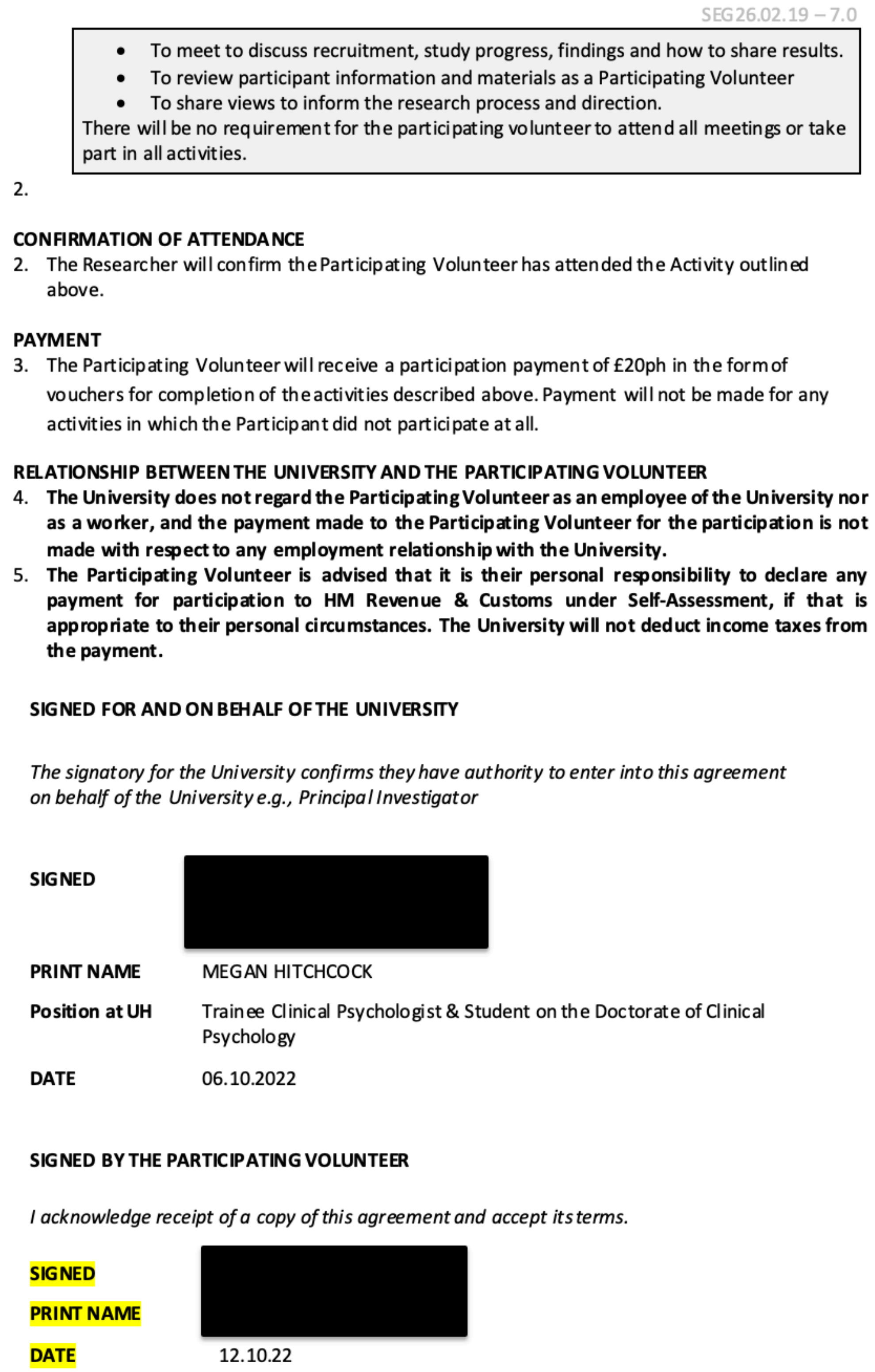
Email Address

ACTIVITY Volunteer for Doctorate in Clinical Psychology research study

The **Participating Volunteer** has agreed to assist the University by voluntarily taking part in the research **Activity**.

1. The Activity to be undertaken is described below and it is the Activity for which you have given your consent/agreement.

1



SEG26.02.19 – 7.0

- To meet to discuss recruitment, study progress, findings and how to share results.
- To review participant information and materials as a Participating Volunteer
- To share views to inform the research process and direction.

There will be no requirement for the participating volunteer to attend all meetings or take part in all activities.

2.

CONFIRMATION OF ATTENDANCE

2. The Researcher will confirm the Participating Volunteer has attended the Activity outlined above.

PAYMENT

3. The Participating Volunteer will receive a participation payment of £20ph in the form of vouchers for completion of the activities described above. Payment will not be made for any activities in which the Participant did not participate at all.

RELATIONSHIP BETWEEN THE UNIVERSITY AND THE PARTICIPATING VOLUNTEER

4. **The University does not regard the Participating Volunteer as an employee of the University nor as a worker, and the payment made to the Participating Volunteer for the participation is not made with respect to any employment relationship with the University.**
5. **The Participating Volunteer is advised that it is their personal responsibility to declare any payment for participation to HM Revenue & Customs under Self-Assessment, if that is appropriate to their personal circumstances. The University will not deduct income taxes from the payment.**

SIGNED FOR AND ON BEHALF OF THE UNIVERSITY

The signatory for the University confirms they have authority to enter into this agreement on behalf of the University e.g., Principal Investigator

SIGNED [redacted]

PRINT NAME MEGAN HITCHCOCK

Position at UH Trainee Clinical Psychologist & Student on the Doctorate of Clinical Psychology

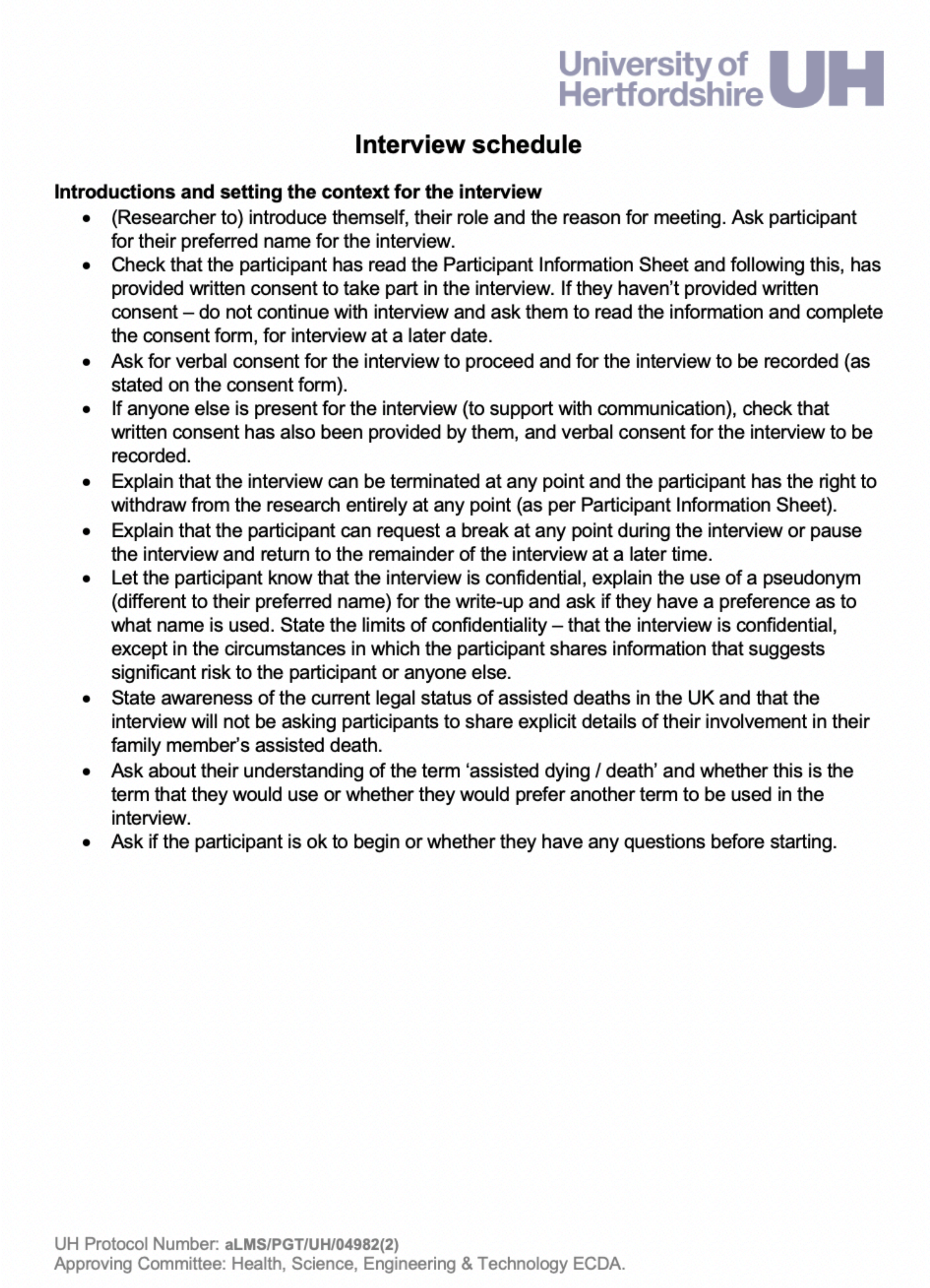
DATE 06.10.2022

SIGNED BY THE PARTICIPATING VOLUNTEER

I acknowledge receipt of a copy of this agreement and accept its terms.

SIGNED
PRINT NAME [redacted]
DATE 12.10.22

Appendix D: Interview schedule



University of Hertfordshire UH

Interview schedule

Introductions and setting the context for the interview

- (Researcher to) introduce themself, their role and the reason for meeting. Ask participant for their preferred name for the interview.
- Check that the participant has read the Participant Information Sheet and following this, has provided written consent to take part in the interview. If they haven't provided written consent – do not continue with interview and ask them to read the information and complete the consent form, for interview at a later date.
- Ask for verbal consent for the interview to proceed and for the interview to be recorded (as stated on the consent form).
- If anyone else is present for the interview (to support with communication), check that written consent has also been provided by them, and verbal consent for the interview to be recorded.
- Explain that the interview can be terminated at any point and the participant has the right to withdraw from the research entirely at any point (as per Participant Information Sheet).
- Explain that the participant can request a break at any point during the interview or pause the interview and return to the remainder of the interview at a later time.
- Let the participant know that the interview is confidential, explain the use of a pseudonym (different to their preferred name) for the write-up and ask if they have a preference as to what name is used. State the limits of confidentiality – that the interview is confidential, except in the circumstances in which the participant shares information that suggests significant risk to the participant or anyone else.
- State awareness of the current legal status of assisted deaths in the UK and that the interview will not be asking participants to share explicit details of their involvement in their family member's assisted death.
- Ask about their understanding of the term 'assisted dying / death' and whether this is the term that they would use or whether they would prefer another term to be used in the interview.
- Ask if the participant is ok to begin or whether they have any questions before starting.

UH Protocol Number: **aLMS/PGT/UH/04982(2)**
Approving Committee: Health, Science, Engineering & Technology ECDA.

Pre-interview questionnaire
[To be asked by researcher at start of interview]

- Ahead of the interview it would be helpful to gather some information about you, and the person in your family who had an assisted death.
- I understand some of these questions might feel quite personal, this information is important to capture to help with understanding the perspectives shared in this study and will also be used to guide the interview questions.

Name:
Date today:

How old are you?
(years)

How would you describe your gender?
(e.g. female, male, non-binary etc.)

How would you describe your ethnicity?
(e.g. White British, Black British, Mixed etc.)

How would you describe your religious beliefs?
(e.g. Muslim, Christian, Atheist etc.)

Today we are going to be talking about your family member who had an assisted death; what name would you like me to use to refer to them in this interview?

Please could you confirm that the assisted death of X took place outside of the UK at an established organisation such as Dignitas, Exit, Pegosos or any other organisation outside of the UK. Please just say yes or no in response to this question without giving further details.
YES/NO

What is your relationship to X who had an assisted death?
(e.g. sister, father, daughter, friend, neighbour etc.)

How long ago did X have an assisted death?
(please be as specific as you can e.g. weeks, months)

How involved did you feel in the conversations around X's decision to have an assisted death?

UH Protocol Number: **aLMS/PGT/UH/04982(2)**
Approving Committee: Health, Science, Engineering & Technology ECDA.

(This question is being asked for the sole purpose of helping me to understand how much you felt part of these conversations (or not), in order to help me understand the different perspectives gathered from people participating in the research)

As far as you are aware, was their choice to discuss the decision with you (or not) affected by the current legal status of assisted deaths in the UK?

To your knowledge, who else was aware of your family member's decision to have an assisted death / the reasons for this prior to their death?
(This question is being asked to begin to understand who your family member did / didn't feel able to share this information with - please do not share names, just their relationship to your family member who died e.g. sister 1, sister 2, father, daughter, friend, neighbour etc.)

Since your family member's death, have you been involved in any police investigations surrounding their death? (Please note if this is ongoing you are not able to take part in this research at the current time)
YES/NO

Interview

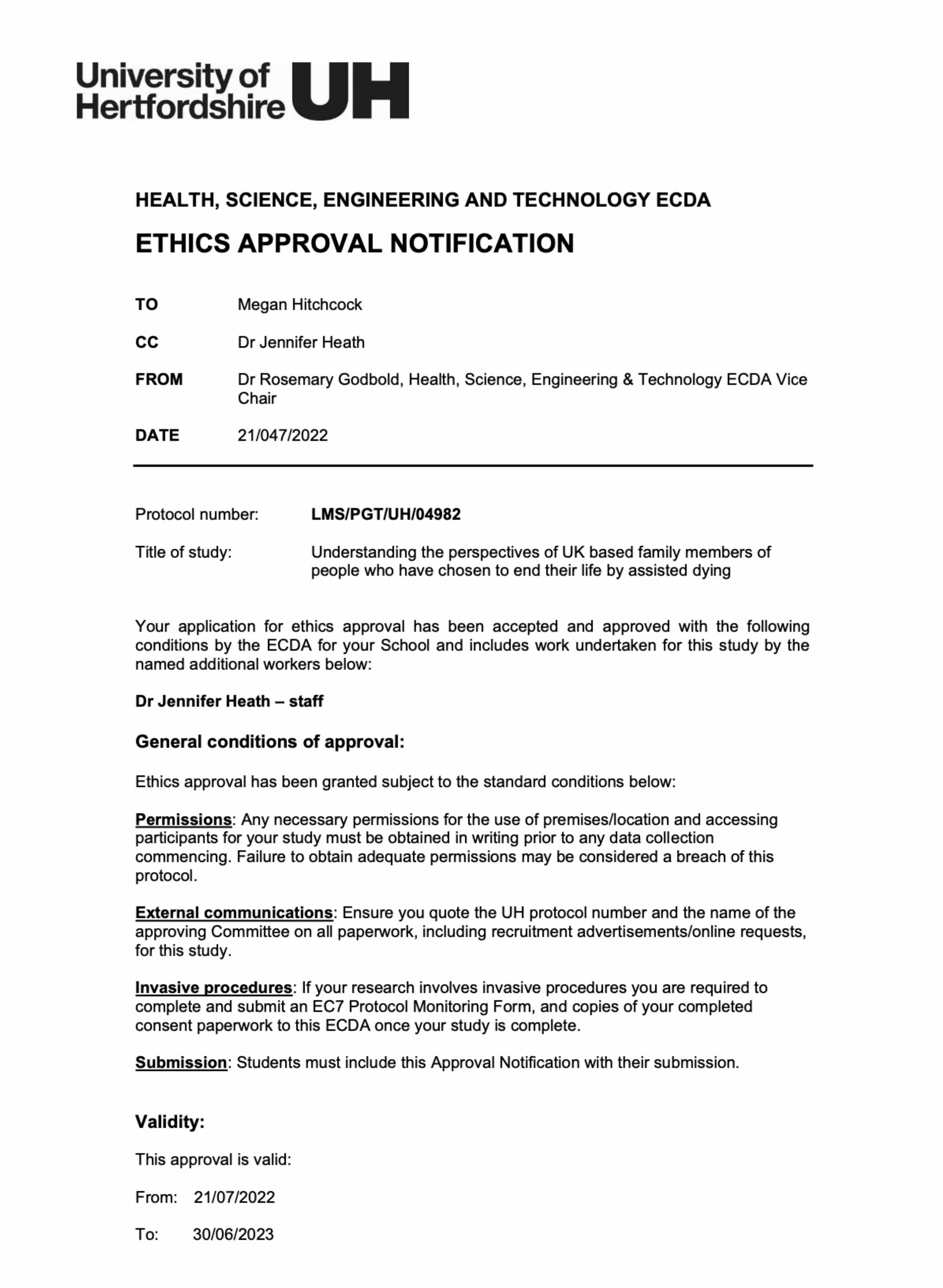
Main research question: **What are UK based family members' perspectives on assisted dying following the assisted death of a loved one?** Today we are hoping to understand your perspective on AD, in relation to your experience of X having an AD…		
Sub question 1: What contextual factors inform these perspectives?	**AD in the context of 'unbearable suffering'** Q: How were you affected by the context X was in, which led them to choose an AD?	• Care role? • Emotional impact? • Practical impact?
	AD in the context of relationships Q. What impact has X's AD had on your family relationships?	• How close were you to X? [How regularly did you see / have contact with X before they died?] • What impact did this context (i.e. what has just been described above) have on your relationship with X at the time? • What impact did [X's situation] have on your relationship with other family members/friends?

		• How did this change through the AD process?
	Decision making around AD Q. You've let me know that you <u>were/weren't</u> involved in the conversations around X's decision to have an AD but that Y was. How was it decided who was / wasn't involved in this decision making?	• What impact did being involved/not have on you? • What impact did this have on others in the family?
	AD in the current UK legal context Q. You've let me know that you do / do not believe that this involvement (or not) was related to the legal context in the UK, but that you <u>have/haven't</u> been involved in a police investigation. How has the current legal status in the UK impacted your experience of X's AD?	• How has it impacted your response to X's death? • What impact has this had on accessing support? E.g. speaking to friends / accessing services?
	AD in particular religious contexts / other contexts Q. Are there other important contexts that have influenced your perspectives on X's AD?	• Religion? [link to what they've said above] • Other faith / spirituality? • Culture?
Sub question 2: How do these experiences fit with family members' prior views on death and dying?	Q. How has your experiences around X's AD impacted your views on death and dying?	• What were your views about death / dying before this experience of X choosing an AD? • Has having this experience changed your relationship with life / death? • What meaning have you made of their death and this way they chose to die?
Sub question 3: What resources do families draw on to navigate this period?	Q. What resources have you drawn upon during this period (from finding out that X was considering an AD until now)?	• What has helped you get through this time? • Certain people? Religion / spiritual? • Existing things in your life or new things? • Have these changed pre to post their death?

Ending

- We are coming to the end of the interview now. Is there anything that you feel would be important for me to know that we have missed?
- Thank you for your time today…
- How have you found talking today?
- Would you like me to give you a call tomorrow to check in on how you are after our talking today? (If yes – arrange a time to call; if no – check whether the participant has someone else who can support them / they can speak to if needed after the interview). You can also contact me at any time via email if you have any questions about the study.
- Explain about debrief sheet (give to participant).
- Explain what will happen next with the study – confirm (if box ticked on consent form) that the participant is still happy to be contacted again for member checking
- Are you interested in being contacted in the future to receive feedback about the outcome of this study?
    - If yes – confirm contact details (email address / telephone number)

Appendix E: Initial ethical approval confirmation



University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO Megan Hitchcock

CC Dr Jennifer Heath

FROM Dr Rosemary Godbold, Health, Science, Engineering & Technology ECDA Vice Chair

DATE 21/047/2022

Protocol number: **LMS/PGT/UH/04982**

Title of study: Understanding the perspectives of UK based family members of people who have chosen to end their life by assisted dying

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Jennifer Heath – staff

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

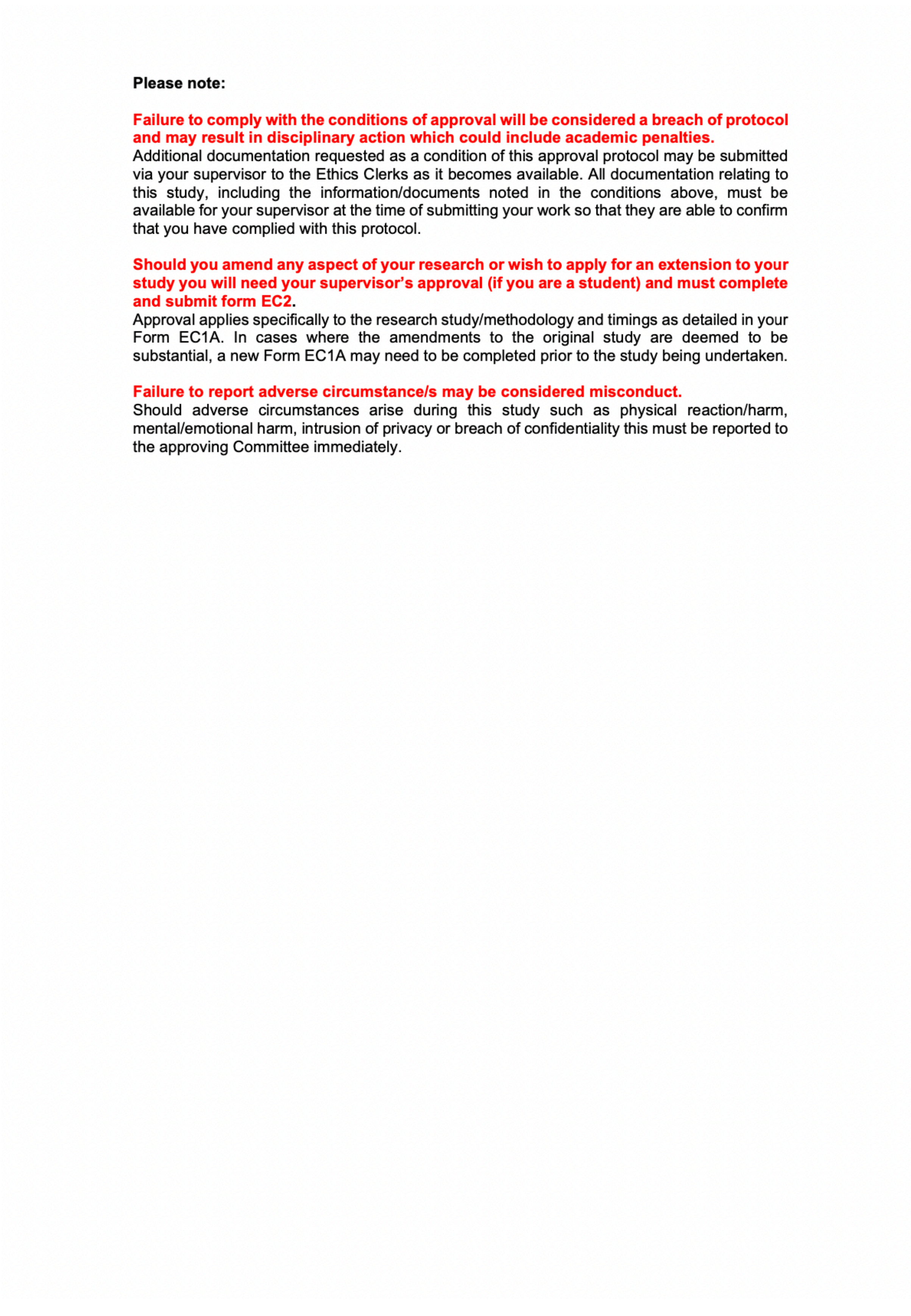
Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 21/07/2022

To: 30/06/2023



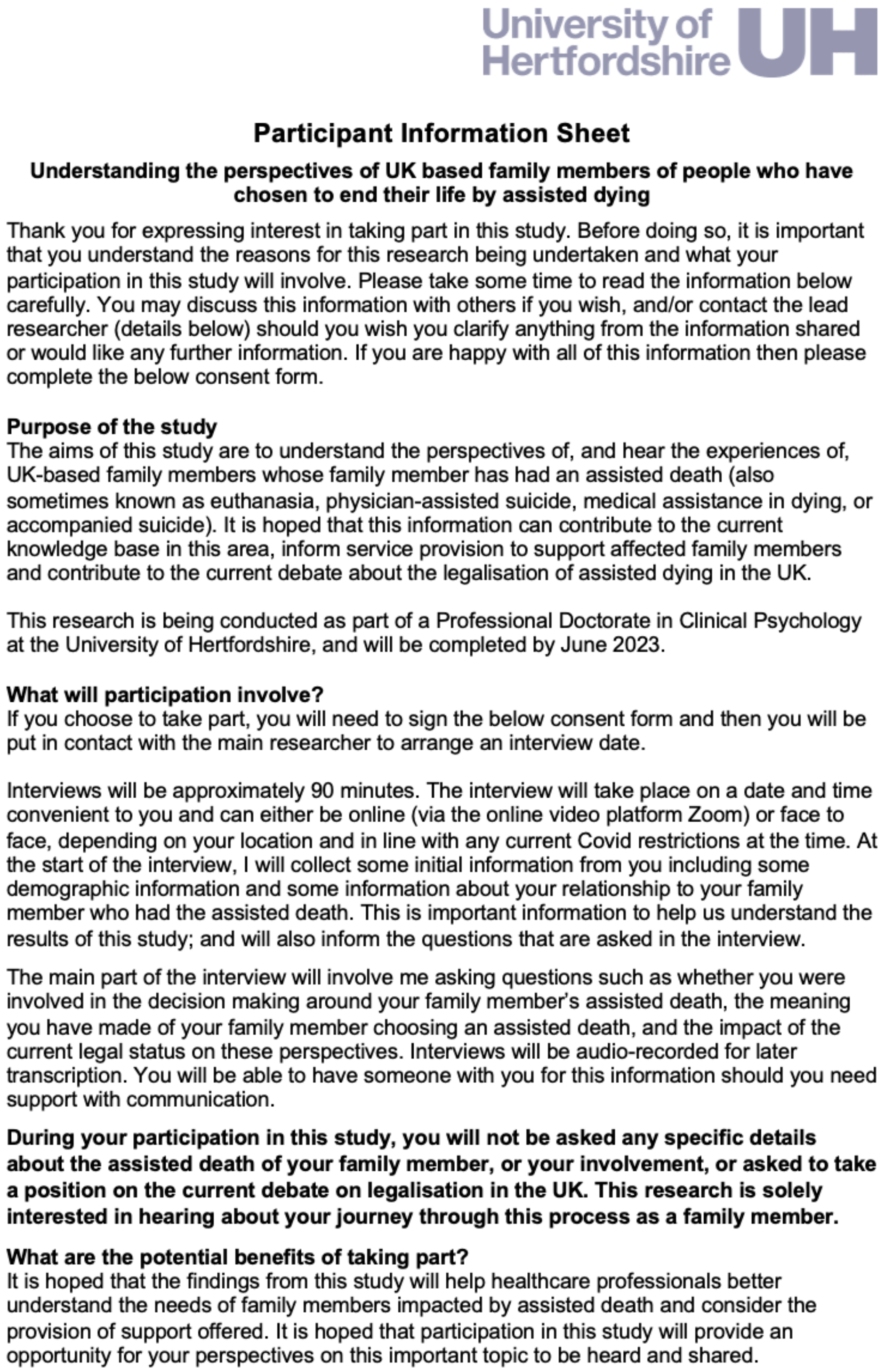
Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit form EC2.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix F: Participant Information Sheet



University of Hertfordshire UH

Participant Information Sheet

Understanding the perspectives of UK based family members of people who have chosen to end their life by assisted dying

Thank you for expressing interest in taking part in this study. Before doing so, it is important that you understand the reasons for this research being undertaken and what your participation in this study will involve. Please take some time to read the information below carefully. You may discuss this information with others if you wish, and/or contact the lead researcher (details below) should you wish you clarify anything from the information shared or would like any further information. If you are happy with all of this information then please complete the below consent form.

Purpose of the study
The aims of this study are to understand the perspectives of, and hear the experiences of, UK-based family members whose family member has had an assisted death (also sometimes known as euthanasia, physician-assisted suicide, medical assistance in dying, or accompanied suicide). It is hoped that this information can contribute to the current knowledge base in this area, inform service provision to support affected family members and contribute to the current debate about the legalisation of assisted dying in the UK.

This research is being conducted as part of a Professional Doctorate in Clinical Psychology at the University of Hertfordshire, and will be completed by June 2023.

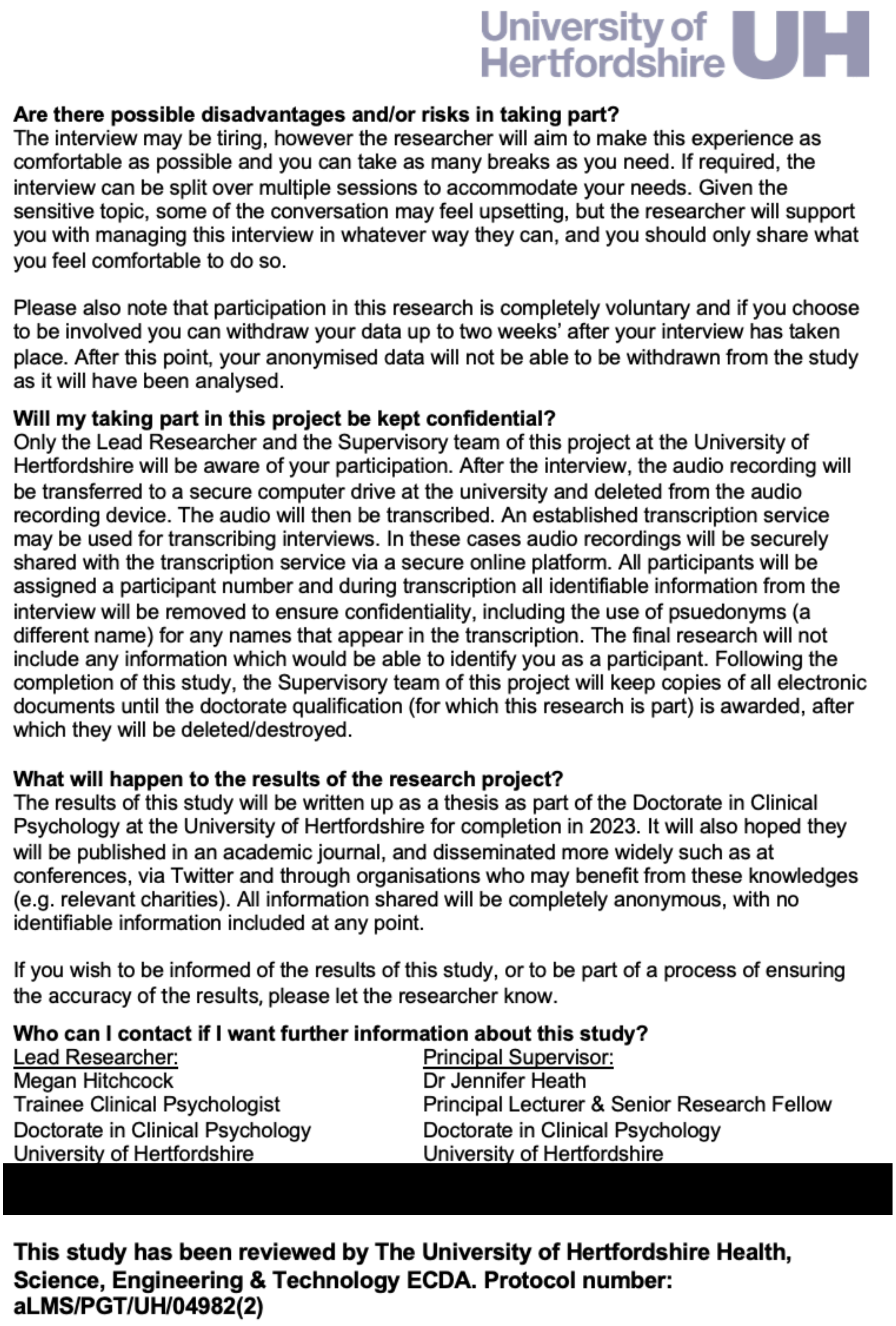
What will participation involve?
If you choose to take part, you will need to sign the below consent form and then you will be put in contact with the main researcher to arrange an interview date.

Interviews will be approximately 90 minutes. The interview will take place on a date and time convenient to you and can either be online (via the online video platform Zoom) or face to face, depending on your location and in line with any current Covid restrictions at the time. At the start of the interview, I will collect some initial information from you including some demographic information and some information about your relationship to your family member who had the assisted death. This is important information to help us understand the results of this study; and will also inform the questions that are asked in the interview.

The main part of the interview will involve me asking questions such as whether you were involved in the decision making around your family member's assisted death, the meaning you have made of your family member choosing an assisted death, and the impact of the current legal status on these perspectives. Interviews will be audio-recorded for later transcription. You will be able to have someone with you for this information should you need support with communication.

During your participation in this study, you will not be asked any specific details about the assisted death of your family member, or your involvement, or asked to take a position on the current debate on legalisation in the UK. This research is solely interested in hearing about your journey through this process as a family member.

What are the potential benefits of taking part?
It is hoped that the findings from this study will help healthcare professionals better understand the needs of family members impacted by assisted death and consider the provision of support offered. It is hoped that participation in this study will provide an opportunity for your perspectives on this important topic to be heard and shared.



Are there possible disadvantages and/or risks in taking part?

The interview may be tiring, however the researcher will aim to make this experience as comfortable as possible and you can take as many breaks as you need. If required, the interview can be split over multiple sessions to accommodate your needs. Given the sensitive topic, some of the conversation may feel upsetting, but the researcher will support you with managing this interview in whatever way they can, and you should only share what you feel comfortable to do so.

Please also note that participation in this research is completely voluntary and if you choose to be involved you can withdraw your data up to two weeks’ after your interview has taken place. After this point, your anonymised data will not be able to be withdrawn from the study as it will have been analysed.

Will my taking part in this project be kept confidential?

Only the Lead Researcher and the Supervisory team of this project at the University of Hertfordshire will be aware of your participation. After the interview, the audio recording will be transferred to a secure computer drive at the university and deleted from the audio recording device. The audio will then be transcribed. An established transcription service may be used for transcribing interviews. In these cases audio recordings will be securely shared with the transcription service via a secure online platform. All participants will be assigned a participant number and during transcription all identifiable information from the interview will be removed to ensure confidentiality, including the use of psuedonyms (a different name) for any names that appear in the transcription. The final research will not include any information which would be able to identify you as a participant. Following the completion of this study, the Supervisory team of this project will keep copies of all electronic documents until the doctorate qualification (for which this research is part) is awarded, after which they will be deleted/destroyed.

What will happen to the results of the research project?

The results of this study will be written up as a thesis as part of the Doctorate in Clinical Psychology at the University of Hertfordshire for completion in 2023. It will also hoped they will be published in an academic journal, and disseminated more widely such as at conferences, via Twitter and through organisations who may benefit from these knowledges (e.g. relevant charities). All information shared will be completely anonymous, with no identifiable information included at any point.

If you wish to be informed of the results of this study, or to be part of a process of ensuring the accuracy of the results, please let the researcher know.

Who can I contact if I want further information about this study?

Lead Researcher:	Principal Supervisor:
Megan Hitchcock	Dr Jennifer Heath
Trainee Clinical Psychologist	Principal Lecturer & Senior Research Fellow
Doctorate in Clinical Psychology	Doctorate in Clinical Psychology
University of Hertfordshire	University of Hertfordshire

[redacted]

This study has been reviewed by The University of Hertfordshire Health, Science, Engineering & Technology ECDA. Protocol number: aLMS/PGT/UH/04982(2)

University of Hertfordshire UH

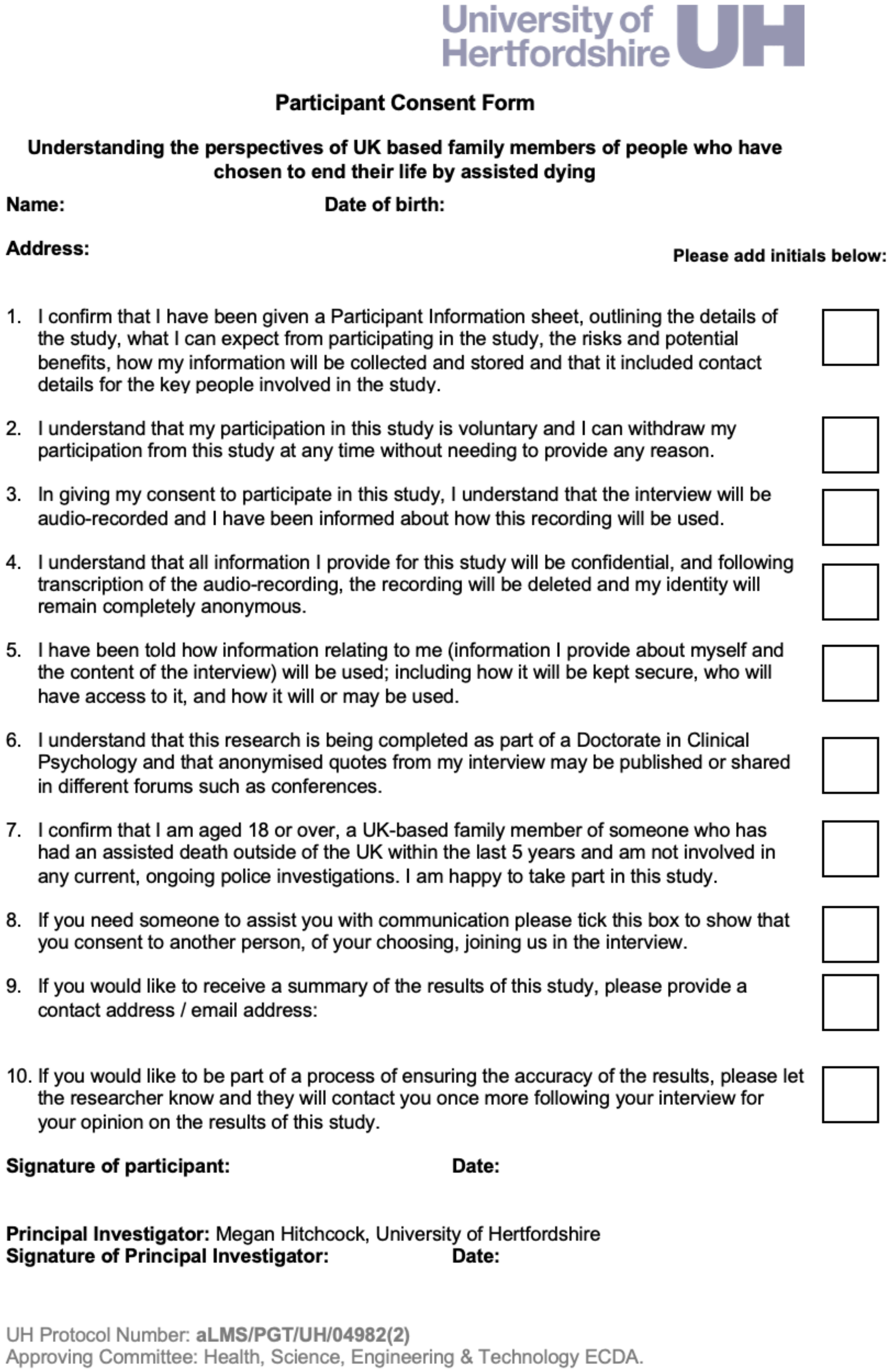
Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

[redacted]

What happens next?
If you are interested in taking part in the study, please complete a consent form. Completing this form indicates that you have read this participant information sheet and that you give your consent to take part in the study. If you are not interested in participating in this study, you do not need to do anything further.

Thank you for taking the time to read this information and for considering participation in this study.

Appendix G: Participant consent form



University of Hertfordshire UH

Participant Consent Form

Understanding the perspectives of UK based family members of people who have chosen to end their life by assisted dying

Name: **Date of birth:**

Address:

Please add initials below:

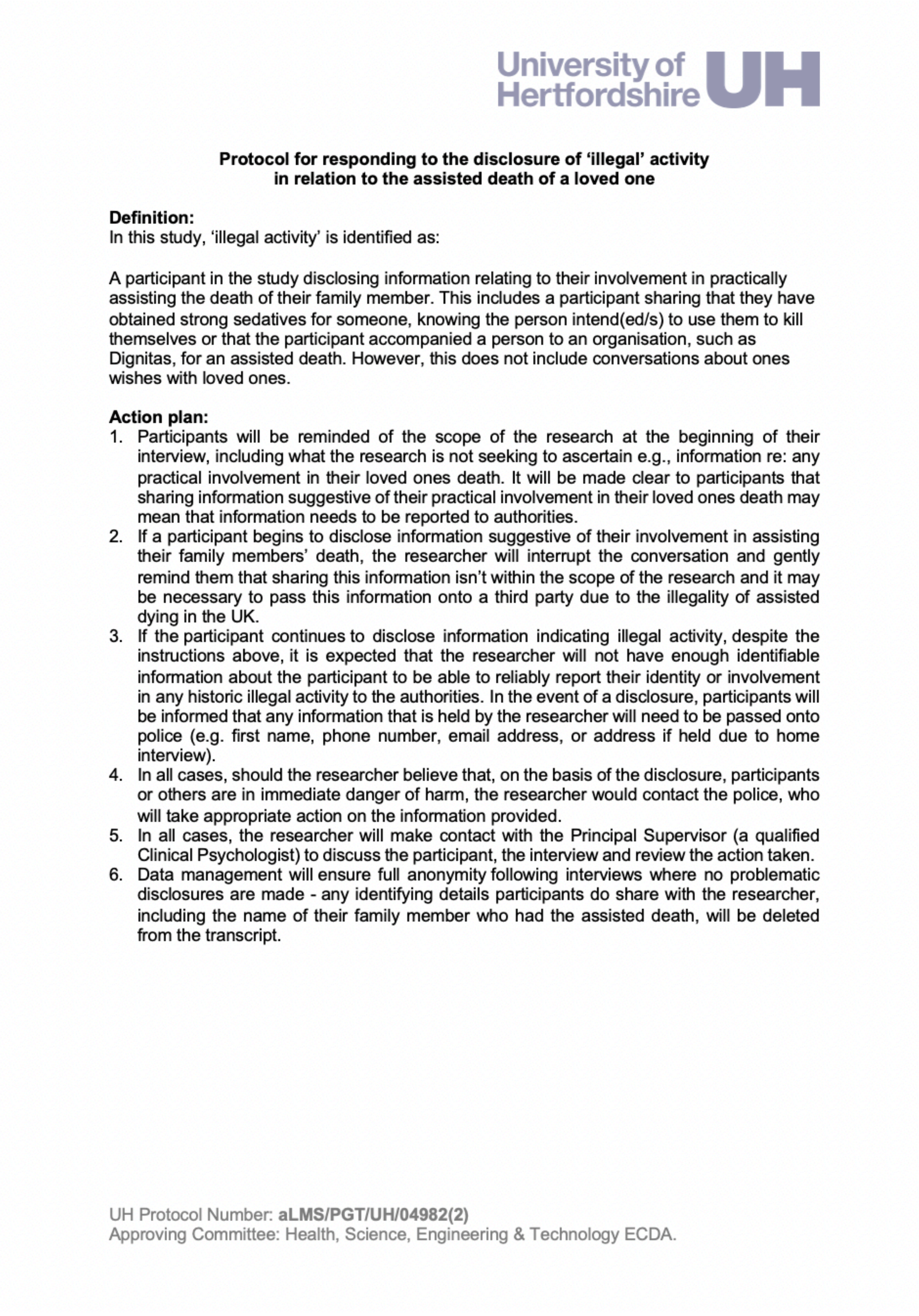
1. I confirm that I have been given a Participant Information sheet, outlining the details of the study, what I can expect from participating in the study, the risks and potential benefits, how my information will be collected and stored and that it included contact details for the key people involved in the study. ☐
2. I understand that my participation in this study is voluntary and I can withdraw my participation from this study at any time without needing to provide any reason. ☐
3. In giving my consent to participate in this study, I understand that the interview will be audio-recorded and I have been informed about how this recording will be used. ☐
4. I understand that all information I provide for this study will be confidential, and following transcription of the audio-recording, the recording will be deleted and my identity will remain completely anonymous. ☐
5. I have been told how information relating to me (information I provide about myself and the content of the interview) will be used; including how it will be kept secure, who will have access to it, and how it will or may be used. ☐
6. I understand that this research is being completed as part of a Doctorate in Clinical Psychology and that anonymised quotes from my interview may be published or shared in different forums such as conferences. ☐
7. I confirm that I am aged 18 or over, a UK-based family member of someone who has had an assisted death outside of the UK within the last 5 years and am not involved in any current, ongoing police investigations. I am happy to take part in this study. ☐
8. If you need someone to assist you with communication please tick this box to show that you consent to another person, of your choosing, joining us in the interview. ☐
9. If you would like to receive a summary of the results of this study, please provide a contact address / email address: ☐
10. If you would like to be part of a process of ensuring the accuracy of the results, please let the researcher know and they will contact you once more following your interview for your opinion on the results of this study. ☐

Signature of participant: **Date:**

Principal Investigator: Megan Hitchcock, University of Hertfordshire
Signature of Principal Investigator: **Date:**

UH Protocol Number: **aLMS/PGT/UH/04982(2)**
Approving Committee: Health, Science, Engineering & Technology ECDA.

Appendix H: Disclosure protocol



University of Hertfordshire UH

Protocol for responding to the disclosure of 'illegal' activity in relation to the assisted death of a loved one

Definition:
In this study, 'illegal activity' is identified as:

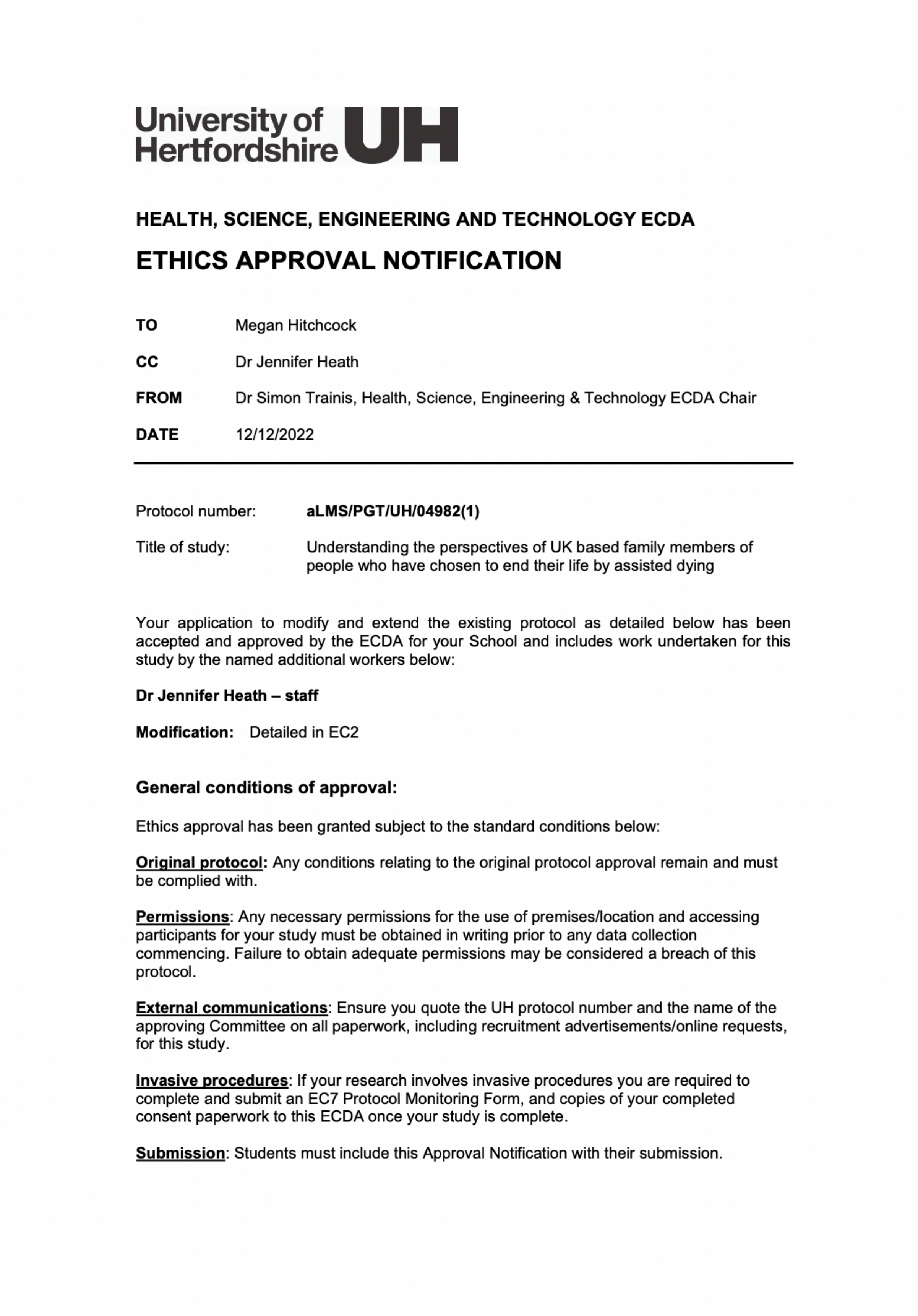
A participant in the study disclosing information relating to their involvement in practically assisting the death of their family member. This includes a participant sharing that they have obtained strong sedatives for someone, knowing the person intend(ed/s) to use them to kill themselves or that the participant accompanied a person to an organisation, such as Dignitas, for an assisted death. However, this does not include conversations about ones wishes with loved ones.

Action plan:

1. Participants will be reminded of the scope of the research at the beginning of their interview, including what the research is not seeking to ascertain e.g., information re: any practical involvement in their loved ones death. It will be made clear to participants that sharing information suggestive of their practical involvement in their loved ones death may mean that information needs to be reported to authorities.
2. If a participant begins to disclose information suggestive of their involvement in assisting their family members' death, the researcher will interrupt the conversation and gently remind them that sharing this information isn't within the scope of the research and it may be necessary to pass this information onto a third party due to the illegality of assisted dying in the UK.
3. If the participant continues to disclose information indicating illegal activity, despite the instructions above, it is expected that the researcher will not have enough identifiable information about the participant to be able to reliably report their identity or involvement in any historic illegal activity to the authorities. In the event of a disclosure, participants will be informed that any information that is held by the researcher will need to be passed onto police (e.g. first name, phone number, email address, or address if held due to home interview).
4. In all cases, should the researcher believe that, on the basis of the disclosure, participants or others are in immediate danger of harm, the researcher would contact the police, who will take appropriate action on the information provided.
5. In all cases, the researcher will make contact with the Principal Supervisor (a qualified Clinical Psychologist) to discuss the participant, the interview and review the action taken.
6. Data management will ensure full anonymity following interviews where no problematic disclosures are made - any identifying details participants do share with the researcher, including the name of their family member who had the assisted death, will be deleted from the transcript.

UH Protocol Number: **aLMS/PGT/UH/04982(2)**
Approving Committee: Health, Science, Engineering & Technology ECDA.

Appendix I: Ethical approval confirmation after amendment 1



University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Megan Hitchcock
CC	Dr Jennifer Heath
FROM	Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair
DATE	12/12/2022

Protocol number:	**aLMS/PGT/UH/04982(1)**
Title of study:	Understanding the perspectives of UK based family members of people who have chosen to end their life by assisted dying

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Jennifer Heath – staff

Modification: Detailed in EC2

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

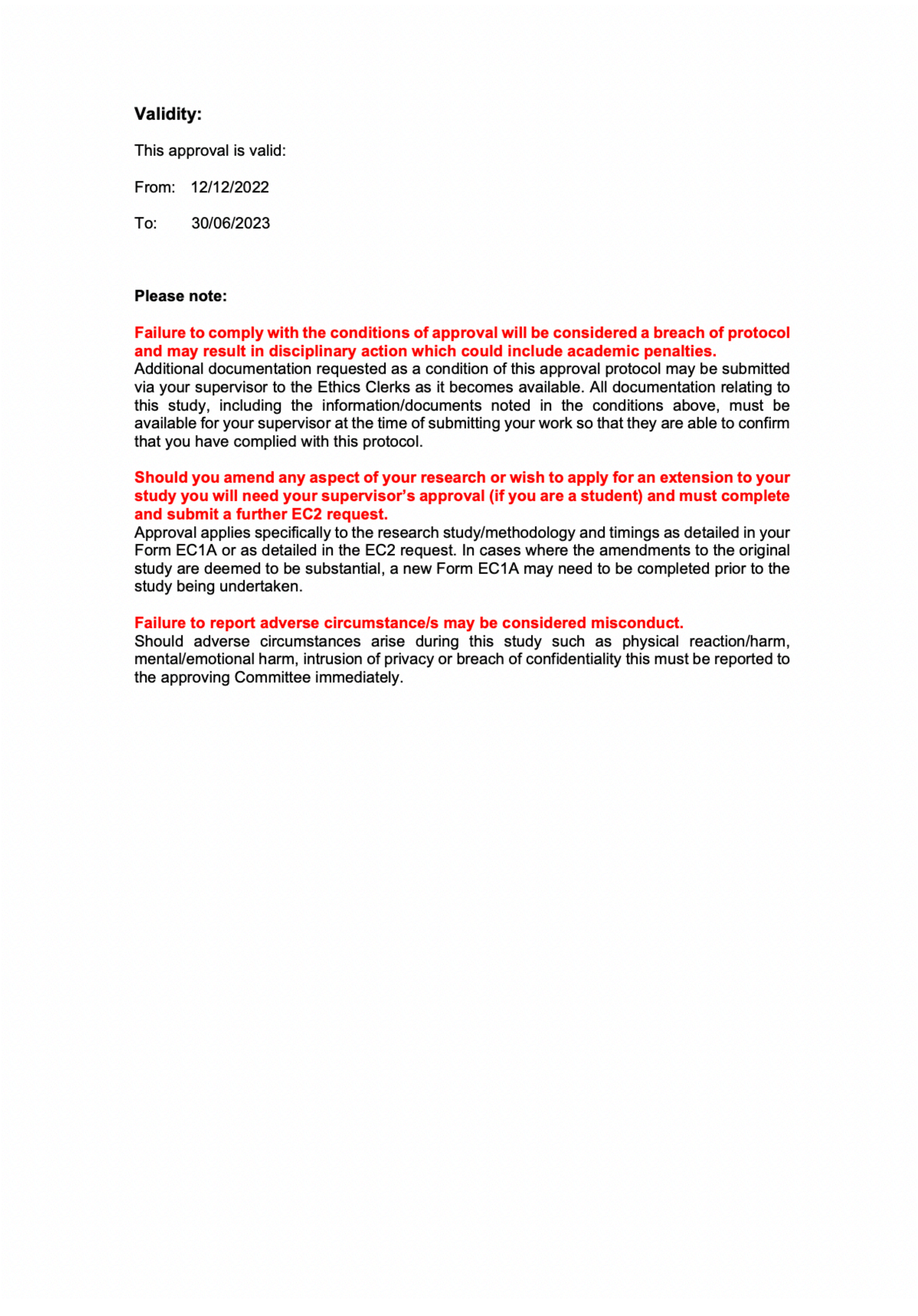
Original protocol: Any conditions relating to the original protocol approval remain and must be complied with.

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.



Validity:

This approval is valid:

From: 12/12/2022

To: 30/06/2023

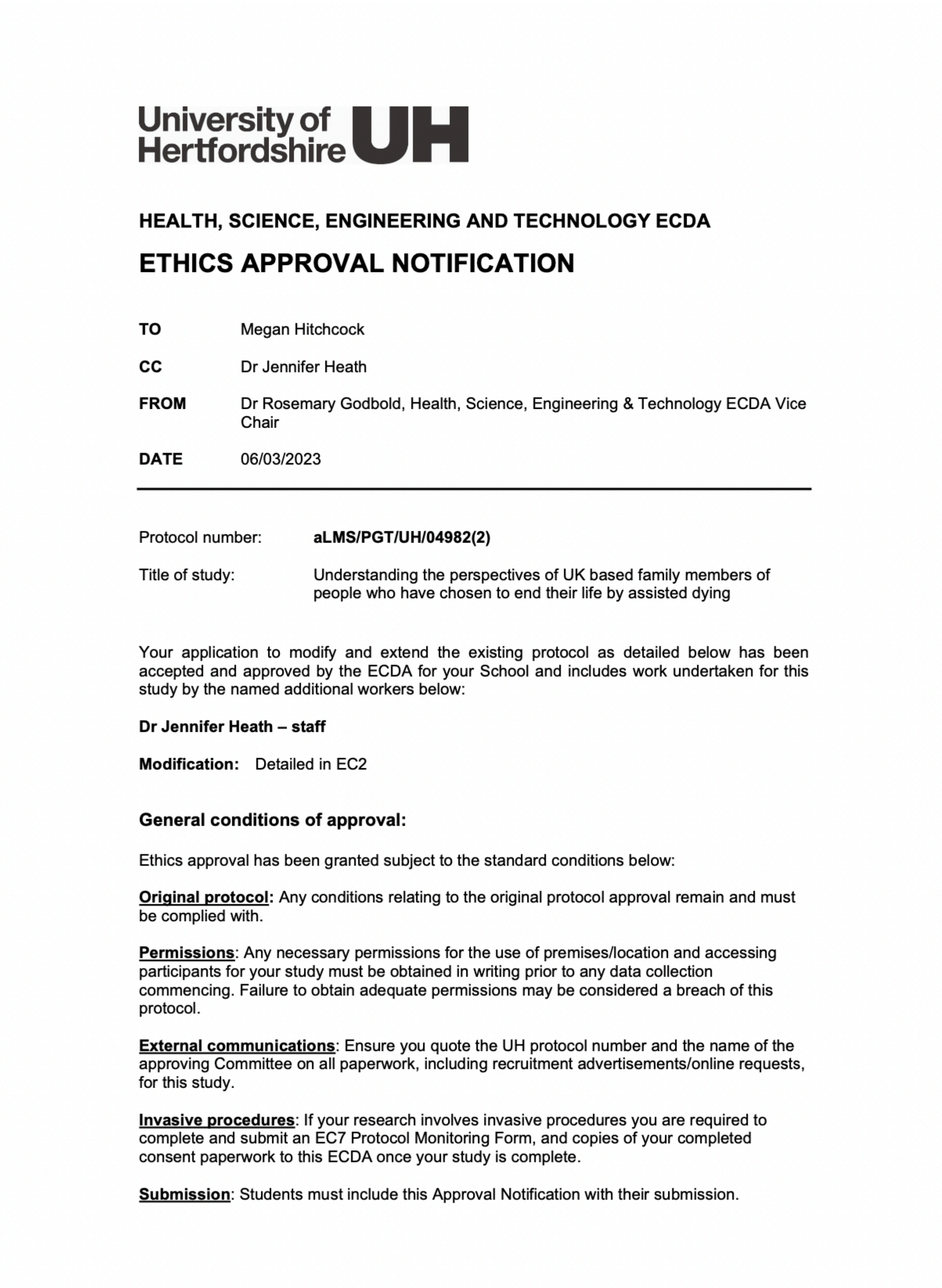
Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit a further EC2 request.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A or as detailed in the EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix J: Ethical approval confirmation after amendment 2



University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO Megan Hitchcock

CC Dr Jennifer Heath

FROM Dr Rosemary Godbold, Health, Science, Engineering & Technology ECDA Vice Chair

DATE 06/03/2023

Protocol number: **aLMS/PGT/UH/04982(2)**

Title of study: Understanding the perspectives of UK based family members of people who have chosen to end their life by assisted dying

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Jennifer Heath – staff

Modification: Detailed in EC2

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

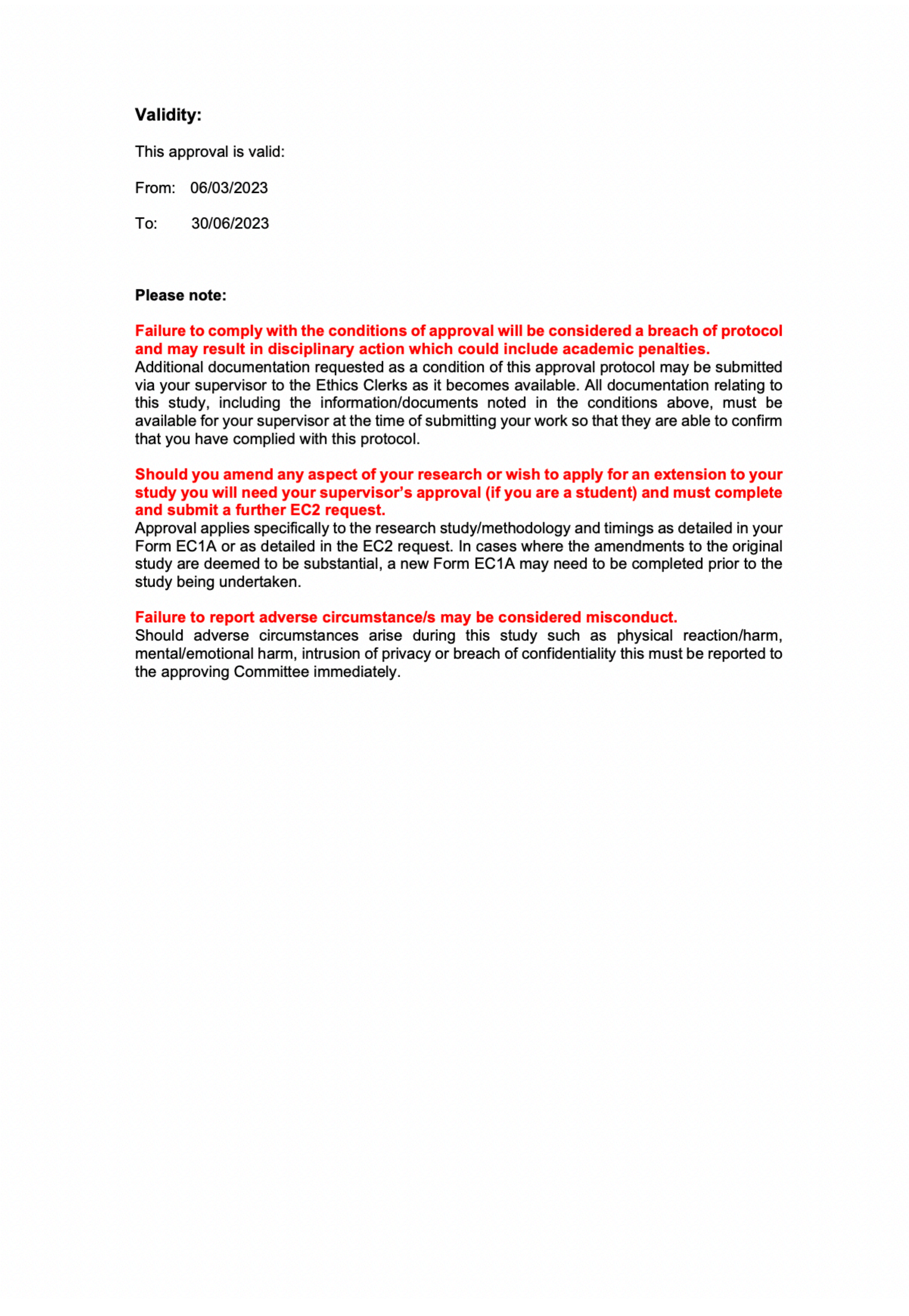
Original protocol: Any conditions relating to the original protocol approval remain and must be complied with.

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.



Validity:

This approval is valid:

From: 06/03/2023

To: 30/06/2023

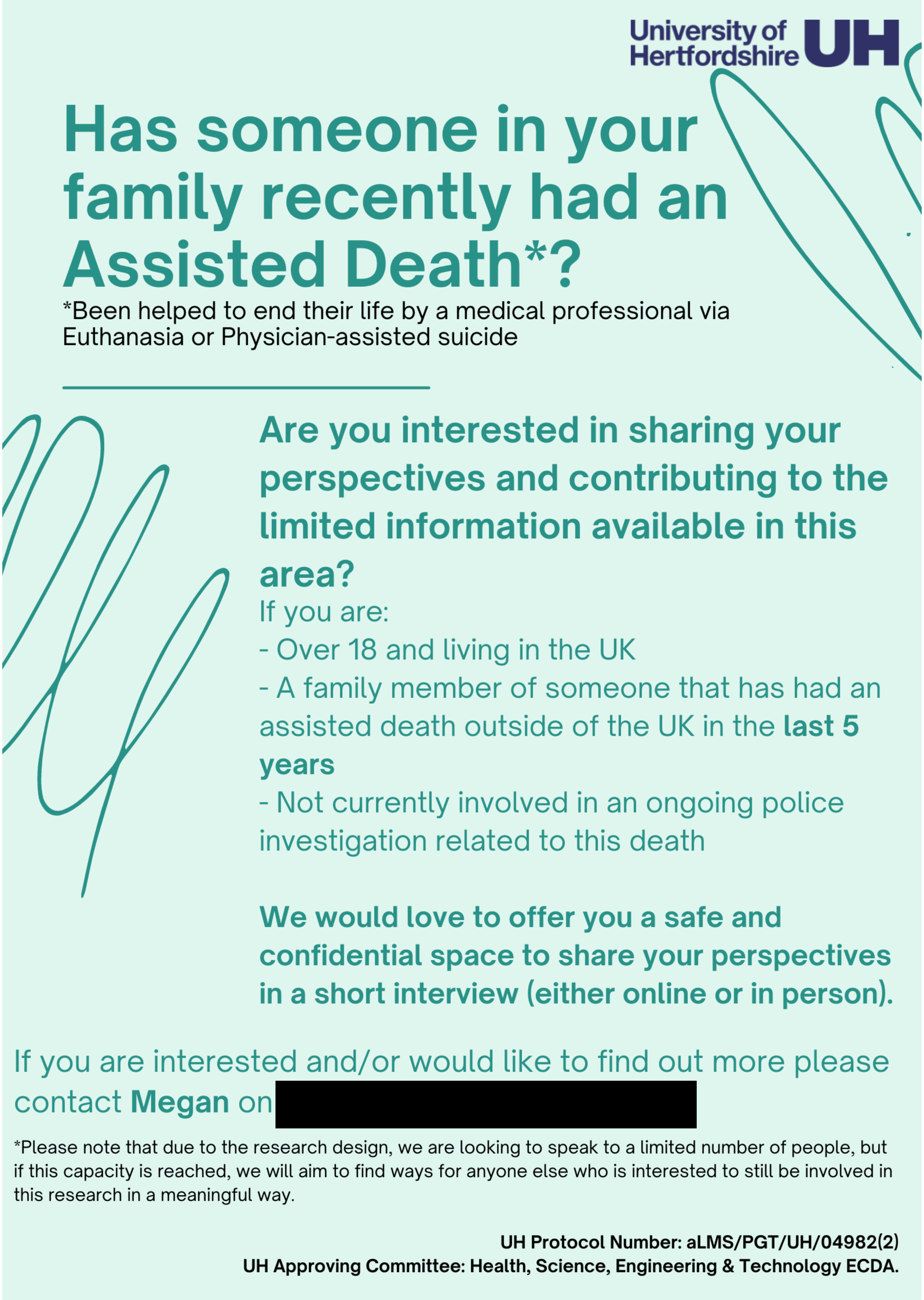
Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit a further EC2 request.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A or as detailed in the EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix K: Participant recruitment poster



University of Hertfordshire UH

Has someone in your family recently had an Assisted Death*?

*Been helped to end their life by a medical professional via Euthanasia or Physician-assisted suicide

---

Are you interested in sharing your perspectives and contributing to the limited information available in this area?

If you are:

- Over 18 and living in the UK
- A family member of someone that has had an assisted death outside of the UK in the **last 5 years**
- Not currently involved in an ongoing police investigation related to this death

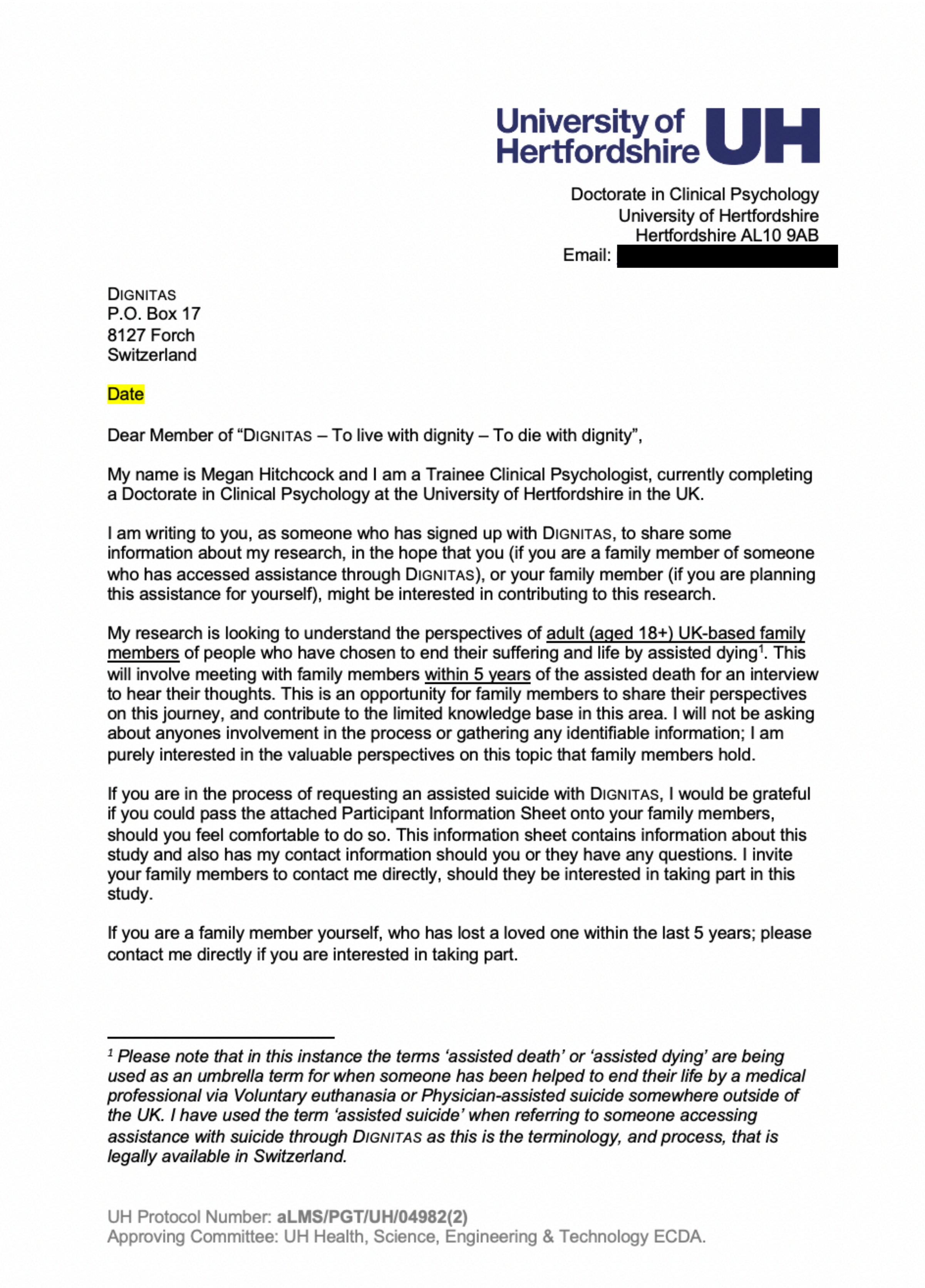
We would love to offer you a safe and confidential space to share your perspectives in a short interview (either online or in person).

If you are interested and/or would like to find out more please contact **Megan** on [redacted]

*Please note that due to the research design, we are looking to speak to a limited number of people, but if this capacity is reached, we will aim to find ways for anyone else who is interested to still be involved in this research in a meaningful way.

UH Protocol Number: aLMS/PGT/UH/04982(2)
UH Approving Committee: Health, Science, Engineering & Technology ECDA.

Appendix L: Dignitas recruitment letter



University of Hertfordshire UH

Doctorate in Clinical Psychology
University of Hertfordshire
Hertfordshire AL10 9AB
Email: [redacted]

Dignitas
P.O. Box 17
8127 Forch
Switzerland

Date

Dear Member of "Dignitas – To live with dignity – To die with dignity",

My name is Megan Hitchcock and I am a Trainee Clinical Psychologist, currently completing a Doctorate in Clinical Psychology at the University of Hertfordshire in the UK.

I am writing to you, as someone who has signed up with Dignitas, to share some information about my research, in the hope that you (if you are a family member of someone who has accessed assistance through Dignitas), or your family member (if you are planning this assistance for yourself), might be interested in contributing to this research.

My research is looking to understand the perspectives of adult (aged 18+) UK-based family members of people who have chosen to end their suffering and life by assisted dying[1]. This will involve meeting with family members within 5 years of the assisted death for an interview to hear their thoughts. This is an opportunity for family members to share their perspectives on this journey, and contribute to the limited knowledge base in this area. I will not be asking about anyones involvement in the process or gathering any identifiable information; I am purely interested in the valuable perspectives on this topic that family members hold.

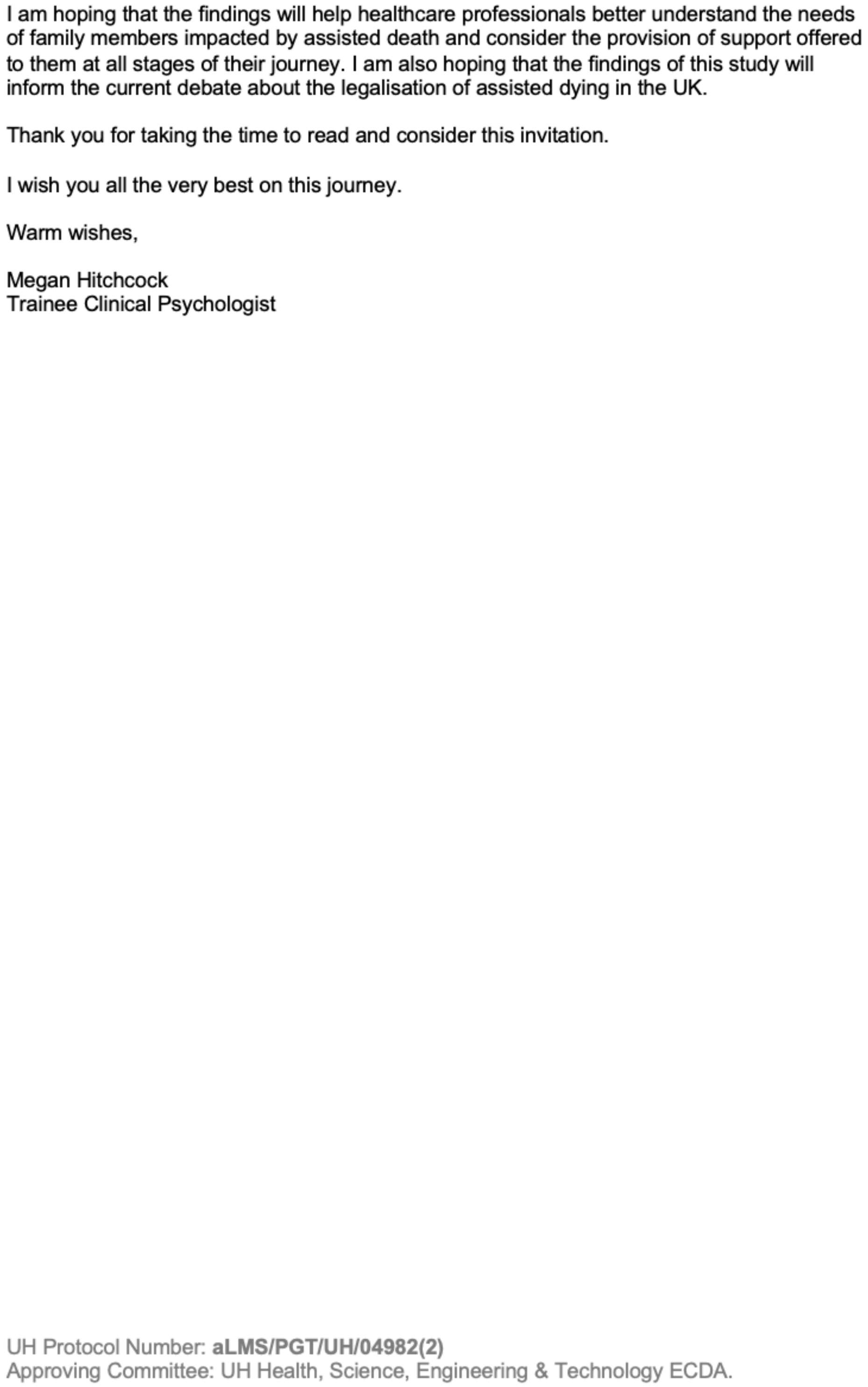
If you are in the process of requesting an assisted suicide with Dignitas, I would be grateful if you could pass the attached Participant Information Sheet onto your family members, should you feel comfortable to do so. This information sheet contains information about this study and also has my contact information should you or they have any questions. I invite your family members to contact me directly, should they be interested in taking part in this study.

If you are a family member yourself, who has lost a loved one within the last 5 years; please contact me directly if you are interested in taking part.

---

[1] *Please note that in this instance the terms 'assisted death' or 'assisted dying' are being used as an umbrella term for when someone has been helped to end their life by a medical professional via Voluntary euthanasia or Physician-assisted suicide somewhere outside of the UK. I have used the term 'assisted suicide' when referring to someone accessing assistance with suicide through Dignitas as this is the terminology, and process, that is legally available in Switzerland.*

UH Protocol Number: **aLMS/PGT/UH/04982(2)**
Approving Committee: UH Health, Science, Engineering & Technology ECDA.



I am hoping that the findings will help healthcare professionals better understand the needs of family members impacted by assisted death and consider the provision of support offered to them at all stages of their journey. I am also hoping that the findings of this study will inform the current debate about the legalisation of assisted dying in the UK.

Thank you for taking the time to read and consider this invitation.

I wish you all the very best on this journey.

Warm wishes,

Megan Hitchcock
Trainee Clinical Psychologist

UH Protocol Number: **aLMS/PGT/UH/04982(2)**
Approving Committee: UH Health, Science, Engineering & Technology ECDA.

Appendix M: Participant debrief sheet

University of Hertfordshire UH

Post-interview Participant Debrief and Information Sheet

Study title: Understanding the perspectives of UK based family members of people who have chosen to end their life by assisted dying

Thank you for taking the time to be part of this study and for making it possible.

Through this study, I am exploring family members' perspectives on assisted dying and the different contexts that contribute to these perspectives. I am interested in the impact that an assisted death has had on family members, and whether this has been impacted by family members' level of involvement in the decision-making process for the assisted death, or by the current legal position within the UK.

Given the current lack of research literature on this topic, I am also hoping that this research will contribute to the knowledge base in this area. Therefore, your contributions will help UK based healthcare services to better understand the needs of family members affected by assisted dying, and in turn, be better placed to support families during and after this period.

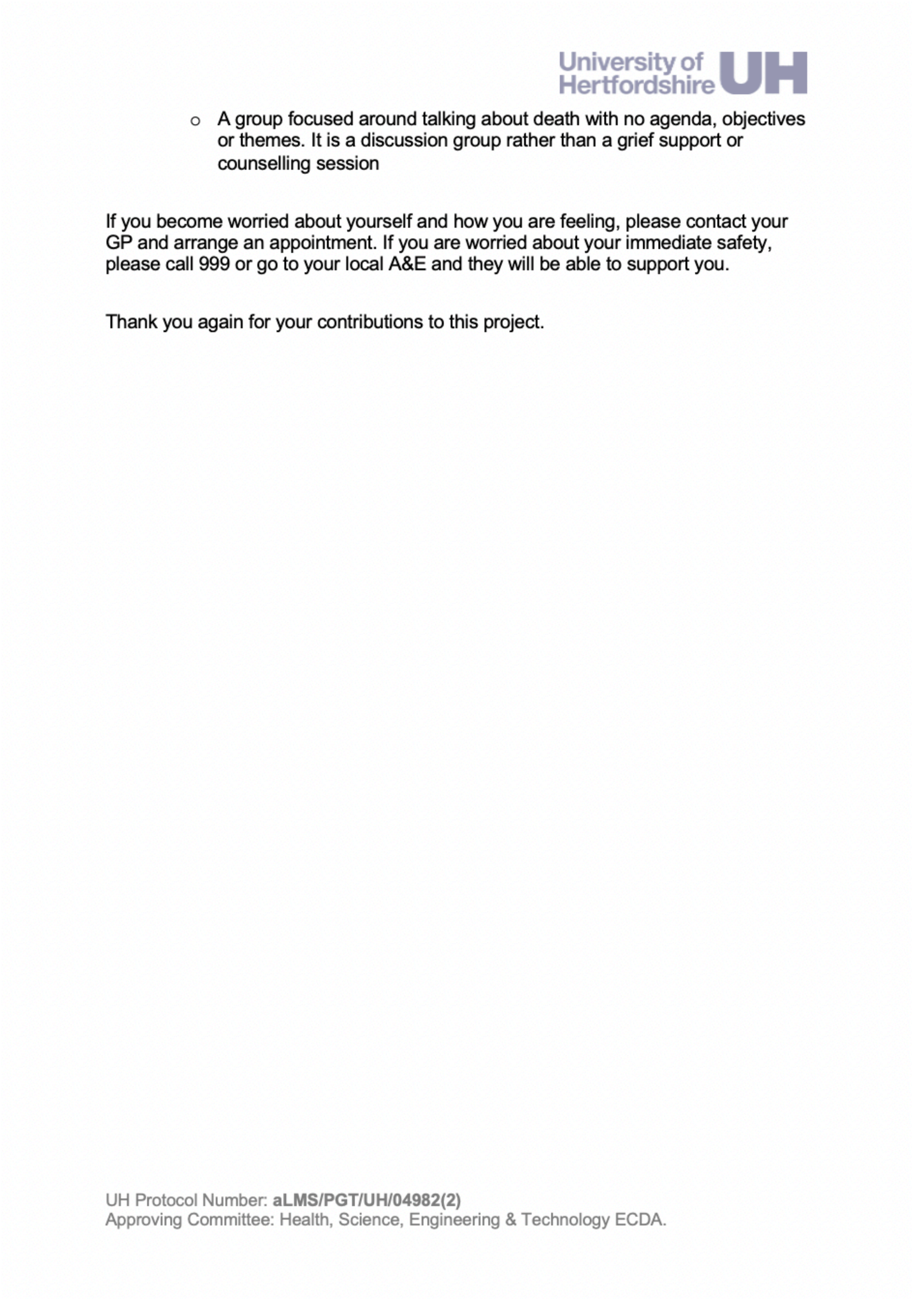
Sources of support

Talking with me today might have left you feeling upset or had an impact on your mood – this is completely understandable, given what we have been talking about together. However, if you continue to feel this way, you may wish to talk with someone about how you're feeling.

Following a bereavement most people seek comfort in family or friends; people that know them and what they have been through. However, there are also a number of national organisations, which you may already be familiar with, which may be helpful to you:

- At a Loss – https://www.ataloss.org/
    - A service that helps bereaved people find support
- Cruse Bereavement Care - https://www.cruse.org.uk/
    - Offers information and support after bereavement
- Dying Matters - https://www.hospiceuk.org/our-campaigns/dying-matters
    - Campaign organisation working to encourage people to talk more openly about death and dying
- The Good Grief Trust - https://www.thegoodgrieftrust.org/
    - A charity run by people who have been bereaved, offering support
- Samaritans - https://www.samaritans.org/ or Freephone 116 123
    - Charity that offers space to talk to anyone who needs it 24/7
- Widowed and Young (WAY) - https://www.widowedandyoung.org.uk/
    - Offers support to anyone aged 50 or younger when their partner died
- Marie Curie - https://www.mariecurie.org.uk/help/support/bereavement
    - Offers a bereavement support service for a bereavement after a terminal illness
- Death Café - https://deathcafe.com/

UH Protocol Number: **aLMS/PGT/UH/04982(2)**
Approving Committee: Health, Science, Engineering & Technology ECDA.



- A group focused around talking about death with no agenda, objectives or themes. It is a discussion group rather than a grief support or counselling session

If you become worried about yourself and how you are feeling, please contact your GP and arrange an appointment. If you are worried about your immediate safety, please call 999 or go to your local A&E and they will be able to support you.

Thank you again for your contributions to this project.

UH Protocol Number: **aLMS/PGT/UH/04982(2)**
Approving Committee: Health, Science, Engineering & Technology ECDA.

Appendix N: Examples of analysed sections of interview transcripts

Transcript extract 1: Page 12	**Exploratory notes**	**Experiential statement**
I: Did [Name], choosing to have an assisted death, have an impact on your relationship and kind of how it was? Or did it kind of stay the same up until…?		
P: Um, well obviously you're living through a time um, how do I put it, for most of your married life you're trudging up a fairly st- sort of steep hill, nothing is easy, you just keep on trudging up that hill,	Experience of married life / life "Trudging up that hill" - Metaphor of life as a journey Steep hill – climb – hard work "Nothing is easy" - life is hard?	Marriage = facing life's challenges together
then suddenly she'd come to the top of her hill and she could see the end point.	Knowing when she will die; certainty around death Change to "she" – shift to being individual people / individual decisions? Suddenly they aren't journeying together? Different paths? Previously not knowing how high the hill was, but now can see the top?	AD changed the course of life; seeing death as the goal
I: Yeah?		
P: And so obviously it makes a big change in your perception of life.	"Obviously" - assumed understanding Seeing life differently? This is new experience / path?	
I: Mmm		
P: Um and I suppose for me too I was wondering how I would… how my life would follow without her	Considering life after her death + the impact of this loss Questioning how the next stage of his life will look Worried about being alone? Intrigued?	Wondering about the next chapter (alone)

I: Mmm		
P: Because although we lived these sort of separate um channels, um we were very close you know and, and um it's, 50 years of it you know – you spend more time with your partner than you do with your parents, and your children… anything else you know,	Separate channels – not life together? Emphasis on very close + significance of time together – companionship? They know each other really well?	Reflecting back on their relationship
um I realised that after her death, umm but umm it's, I think, during the time, if anything, we became closer, um, because, we talked an awful lot about what was ahead.	Connecting through shared experience of planning AD – in it together? "Awful lot" – extent of conversations Only person he could talk to? Only person she could talk to?	Connecting through facing this challenge together
I: Mmm. And what about the impact on um, other family relationships? You've mentioned your two sons? How did…?		
P: Well both my two sons were in the loop from the day she decided that she was going to have an assisted suicide.	"In the loop" – informed? "She decided" – her decision	Recognised it as her decision; telling not asking others
I: Mmm		
P: Um, she rang them up and they came down for supper and she told them then. Of course it was difficult for them, but they'd taken it on board by the time it happened.	Expected son's to find this news difficult "Told" – informing "Taken it on board" – expected them to accept decision? And they did?	Expected decision to be accepted by others

And um, I- there was no argument or disagreement about it. I think um what it was… how do I put it? Throughout our marriage, obviously we've had disagreements, but most of the time we allowed each other to have an opinion. It wasn't always my opinion, it was her opinion and my opinion. And I think the boys grew up knowing this, and of course a lot of the time as they were growing up, I worked as a [job] so I would spend a fair bit of time out of the house, reappearing at weekends sometimes. Um, sometimes even when I was working in [Location] I would be away for a long period during the day and so um, the, the er closeness um that she had with her sons was quite intense because of my absences because of work.	Expected this – in her character? Recognised as individuals – Individual decision? Her sons knew her well – wouldn't be surprised?	The decision fitted with her character (wife): expected

Transcript extract 2: Page 9	**Exploratory notes**	**Experiential statement**
I: How involved did you feel in the conversations around [Name]'s assisted death?		
P: The conversations she had, and the discussions she had, were primarily with me. We did live something of a bubble existence, particularly since Covid, although to a certain extent the original lockdown felt like everybody else, was joining us in our existence, umm, so in that sense, I was very… what word did you use?	Main person wife spoke to about AD "Bubble existence" – isolated? Impact of Covid – everyone else understood their usual constraints? "Existence" – existing rather than living?	Others now understanding their isolated existence
I: I used the word involved I guess just to understand. Some people might have felt that they didn't really know that there anything about the reasons why, or that they weren't part of conversations. It sounds like that wasn't the case?		
P: No, we, we, certainly did talk quite a lot in... So yes, in that sense I was involved in… not so much [Name]'s decision-making,	Making it clear he wasn't involved in the decision itself Sense it was her decision making	It was not his decision
but in… as much being a sounding board, for her.	Letting her air her thoughts to helping her make the decision?	His role was to listen
Personally I felt it was very I'm… I, I'm, I was, you know, I was aware of the way that [Name] made decisions and I felt it was very important that, whatever my feelings were, that it was her decision [tears].	His feelings not important here? Important it was her decision – gravity of decision?	Disregarding his own feelings; prioritising wife's autonomy
And, how much do you say to "what do you think?" "what do you feel?"	Asking questions to help her come to answer	
it was ultimately, whether she was influenced by things I said, it had to be, I mean it was her decision.	Unsure what influence he had "it was her decision" – repeated – strength in that opinion	Questioning his influence
You can't make that decision for somebody else. Umm.	Gravity of decision – has to be individual's decision, no one else's	Gravity of decision requires individual autonomy
I: Did you feel that you were able to share how you felt with her?		

P: Yes. Umm, but I think, we may come onto the sort of chronology, and I'm not talking about specific dates, but in terms of the process of going from, you know, umm, you know, when she first, first mentioned umm, going to Dignitas, you know, and, and the time leading up to that… I'm sorry where am I going with this? Umm, outwardly I think I probably, had a more, you might, what you might call, a more neutral, approach, because I didn't want to express strong opinions either to encourage or discourage her because I didn't want to, I didn't feel that was, that was my role, umm, because, as I said, ultimately, it was a decision she had to make.	"Not talking about specific dates" – assumed limits of our conversation? Time between first mentioning it and AD – long time? "Outwardly... more neutral" – needed to hide his feelings? Worried about his influence Not his decision to make	Concerned about influencing decision
I: Mmm, yeah I really hear that.		
P: Okay, I don't remember what the question was.	-	-
I: Don't worry at all. As far as you're aware, was [Name]'s choice to discuss her decision with you, affected by the current legal status in the UK?		
P: I don't think, in discussing things with me was particularly affected by the current legal status. It made it, it really affected, outside of our, you know, our partnership, both in terms of talking to friends and particularly sort of other, third parties, or umm, that's where it gets really complicated.	Would have discussed with him regardless – "partnership" – in it together Legal status – affected being open with others?	Impact of legal status on talking openly with others
And it is very difficult, because no organisations or groups will umm, really talk to you about it. They will explain what the legal situation is, and they may be a campaigning group who has a, you know, a belief that that the law ought to be changed. That's very different from anybody actually, I mean, providing information or providing anyt-, certainly advice. The word, as soon as you get to the word advice, as opposed to information, then it becomes very tricky.	Seeking guidance – not able to access this Organisations worried about legal implications of helping	Legal status impacted access to guidance
I don't think it affected our conversations, other than, it reinforced the fact that it was, it was important that, the practical arrangements had to be things [Name] did.	Clear that he could not 'assist' in arrangements due to legal situation Worried about possible prosecution?	Avoiding prosecution

Transcript extract 3: Page 18	**Exploratory notes**	**Experiential statement**
I: But how do you think the current legal status has impacted your experiences of [Name]'s assisted death?		
P: If it impacted it at all, it impacted it in terms that fewer people knew about her medical condition… hardly any people were told about her plans.	Less people were told Very few people knew	Keeping 'knowing circle' small
I: Mmm		
P: And that was because, w-we realised that, you know if, um, somebody might for any sort of reason tell the authorities what she planned, somebody might try to stop her.	Didn't want anybody to tell the police her plans "Somebody might stop her" – unsure if people would break trust Didn't want anything to stop AD	Worried about people going to the police
I: Mmm. And how do you think it's impacted your response to her death?		
P: Um, it made, as I said, it reinforced my views about assisted suicide, I thought the-the- whatever, I learnt the realities of it, let's put it that way, and it didn't put me off at all, it um, it made me more of a supporter if you like.	Lived experience reinforced prior views re AD "Realities" of process seen positively Now believes in it more strongly?	Lived experience with wife supports longstanding belief in support of AD
Um, but um, I-I feel the law is in such a sort of jumble anyway – i-i-if you have a chief of police in one county whose a-a bible basher, he might be more, sort of, harder on people who are trying to get this sort of service than one whose not	"Jumble" – current legal situation is confusing "Bible basher" – someone with Christian beliefs? Christians don't approve of ADs? Influence of individual views on how current laws are enforced?	Religious beliefs influence inconsistencies in enforcement of law
And um, I, it seems to be so arbitrary…	Belief that current law is enforced inconsistently	Current law is not clearly enforced
I: Mmm		

P: And I think this is the, one of the problems, in that um, you know, I realise that um… people shy off – I have another friend who wanted, um, an assisted suicide and he had mental-, well he'd suffered from depression from time to time and he had to find a Psychiatrist to write a report um, to say that he was capable of making an autonomous decision. Dignitas asked him to get that report. And he said to me, "I rang the psychiatric department at [Name] Hospital and they put the phone down on me, they won't even talk to me".	Because of legal implications "Shy off" – shy away from their duties? Experience of friend needing psychiatrist report to access AD Medical professionals scared to talk due to professional implications?	Medical professionals shut down conversations about AD
I: Mmm		
P: And in the end he found a private Psychiatrist in London who was prepared t-to write a report for him, or you know, to, to interview him, which he did for over two hours and then write a report.	Private v NHS approaches to supporting ADs – different professional implications?	Accessing supporting documentation only possible privately in some cases
Um [unclear] but then again he could only do it because he could afford it [laughs] this is the ridiculous thing about it at the moment you know, t-to go to Dignitas is you know 12,000 pounds, something like that.	Cost of private healthcare Cost of AD process Exclusive nature of current ADs as result	AD accessible only to those with financial capital
I: So there's a big cost implication as well		
P: Yes, it's almost like private medicine you know isn't it.	(As above)	(As above)

Transcript extract 4: Page 5	**Exploratory notes**	**Experiential statement**
I: How did that context impact you like, emotionally, practically?		
P: Well he was, until about 18 months ago, um he was um, well we could see he was struggling every day, my wife saw it every day, I didn't see it every day. But she saw it every day, and um, um,	Feeling closer than he was? Extent of struggling identified – felt it even if wasn't present?	Global sense of the extent of son's struggles
about 18 months ago, um, we were all sat together and [Name] said he had something he wanted to say, which was that he wanted to depart this world.	Informed of wish for AD "Depart this world" – struggling to say die?	Didn't expect son to want to die
I: Mmm		
P: And um obviously it was a big shock, um	Unexpected news "Obviously" – assumed that anyone would feel the same	(As above)
I: Yeah I bet		
P: And um we, we sort of talked it through, a- we both felt that he, he needed to be supported in every single way possible,	Duty to support son "every single way" – doing everything they could	Supporting son was highest priority
um and um so we, we sorted of tentatively agreed that he um would continue to um you, be looked at by doctors and by this physio lady and so on and follow any um anything that was suggested, which he did, um…	"Tentatively agreed" – was everyone in this agreement? Wanted to cover all other options "He did" – felt that son did want this too	Ensuring that all other options were explored first
I: So practically. I know you mentioned that you were taking him to those sessions, were there other practical things that you were needing to do when [Name] was living with [diagnosis], that to kind of support him? Or was that mostly [Name]?		
P: Um, I think, well, um he'd suffered since the age of 12 or 13, so he'd suffered for half his life with this.	Longstanding suffering	Witnessed son's longstanding suffering
Um and it had gradually got worse and worse, um, there were times when, you know, he couldn't even speak, um, he felt so dreadful. Um.	Condition deteriorating "he couldn't even speak" – describing extent of symptoms "he felt so dreadful" – related to unbearable suffering?	Unbearable deterioration of son's condition
I: And what impact did that have on you? As his Dad?		

P: It just made me feel terribly sad. Um, you know, nobody likes to see their child suffering.	Emotional experience of witnessing this suffering “Nobody likes to” – global experience of being a parent	Sadness in witnessing son’s suffering
I: Mmm		
P: Um, so, um [Name] and I lived in hope that the various tests and so on that we were um being sugges-, that the lady physiotherapist, she was called [Name],	Holding onto hope for resolution – did not want AD Physio as expert who can help?	Expectant in a solution being found
um that she suggested, w-we followed them all um, and you know at great expense um…	Cost of accessing private healthcare – not available on NHS? Willing to spend the money – looking for solution?	Invested in solution (financial)
I: Yeah		
P: We had tests done that got sent off to Germany and various sort of laboratories etcetera, and they came back and sort of said well he’s, there’s some deficiency in this or that, so um,	Explored options outside the UK for alternative solutions to AD Extent of search	Organised extensive searching for answers; looking for answers
so he willingly did that.	Believes that his son wanted to find an alternative solution – wanted to live “willingly” – not forced	Son still looking to be helped (didn’t want to die)

Appendix O: Example of a set of Personal Experiential Themes (PETs)

1. Losing my partner of a lifetime

Reflecting back on the relationship
Losing my partner of a lifetime
Reflecting back on their relationship (M)[9]
Proud of them not having a traditional marriage (M)
Appreciated the independence within the partnership
Choosing to pursue their different interests
Accepted his role within the home
Marriage = facing life's challenges together (M)
The significance of a partner in a lifetime
Benefits of preparing for AD together
Connecting through facing this challenge together
Feeling prepared for the AD journey together, not the next chapter apart

Journey with grief
Sense making through writing
Could prepare for death, not for the loss
Time as healing in grief (M)
Benefits of focusing on what he had, not what he lost
Talking about loss gets easier with time
Seeking support and comfort in time of grief
Connecting through shared grief experience
Not concerned about their being an impact on his sons
Adulthood as autonomous (M)
The certainty of death brings honesty
Questioning whether support would have been helpful at the time
Feeling prepared reduced need for support

Finding purpose in the next chapter
Wondering about the next chapter (alone)
Seeking out new interests to maintain quality of life (M)
Engaging in new hobbies using pre-existing skills
Sense of purpose achieved through engaging in meaningful activities
Motivated by connection and discussion
Importance of being engaged in life – not just passing time (M)
Watching TV as a sign of not achieving; not maintaining quality of life
Benefits of maintaining important friendships and rituals
Purposefully seeking out new friendships

2. Terminal illness: facing death

Facing death
Illness as part of life
Accepting illness as part of life
Cancer treatment brings suffering
Accepting her fate (wife's) (M)
Choosing to avoid suffering from natural dying process (M)

Choosing death
Impressed at wife's decisive decision making

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[9] (M) = merged experiential theme

AD was a courageous decision
His wife was avoiding endings
Not wanting dying to become the focus of conversations
The decision fitted with her character (wife): expected
With the option of AD available, the decision made sense
AD changed the course of life; seeing death as the goal (M)
It was now time for her (his wife's) (M)
Choice of AD not a reflection on quality of NHS care
Medical care saves lives; AD for preventing suffering

3. Navigating unknown perspectives

Sharing with others
Keeping 'knowing circle' small
Recognised it as her decision; telling not asking others (M)
Expected decision to be accepted by others
Informing friends; just asking for understanding
Choosing non-disclosure as worried about possible responses
AD as unexpected, out of the ordinary to others

Role of religion
Chosen different religious path to sisters
Lack of interest or connection to Christianity
Religion through expectation, not out of choice
Religious beliefs influence inconsistencies in enforcement of law

4. Benefits of AD

Witnessing the benefits
Sees the benefits; would choose for himself
Lived experience with wife supports longstanding beliefs in support of AD
Struck by positives of wife's death experience with AD

AD for a 'completed' life
AD as an option as quality of life decreases
Scared for life without quality of life
When life feels like it's completed, why prolong it
Ageing brings death into focus
Accessing AD as a right for those who have "had enough"
Autonomy as human right

Economics
Seeing AD as having economic benefits societally (M)

BUT:
Balancing the benefits with the safeguards needed
Access to AD should be based on capacity
There are safeguards in place
Belief that Dignitas adequately navigates issues of capacity
Legal frameworks around AD should resolve concerns around it
AD only accessible to those with financial capital

5. Challenges posed by current legal status

Avoiding the police
Feeling the need to keep it secret
Worried about people going to the police
Avoiding investigation by the police
Current law is not clearly enforced

Navigating the healthcare system
Accessing supporting documentation only possible privately in some cases
HCPs need to protect themselves against the law
HCPs protecting themselves impacts on individuals trying to access AD
Medical professionals shut down conversations about AD

Appendix P: Summary of results sheet for participants

Understanding the perspectives of UK-based family members of people who have chosen to end their life by assisted dying

Summary of results for participants

Thank you

Firstly, a big thank you for taking the time to participate in this research. The study would not have been possible without you, and I am very grateful for your contributions.

Excitedly, I am now able to share a summary of the results with you. This is for your information only, but if you have any feedback, please do share it with me. It would be greatly appreciated.

Results

Overall, the study found four main themes.

Theme 1: A life dictated by illness

This theme highlights the impacts of a family member receiving and/or living with a life changing medical diagnosis. Consideration was given to what a quality-of-life that feels worth living is, and whether a life feels "valid" when experiencing unbearable suffering. The toll that living with this suffering can take on others was also discussed. It was felt that if someone is lacking quality-of-life and/or seeing themselves as a "burden" and having a negative impact on others, that death can feel like the most compassionate choice.

Theme 2: Life as autonomous

This theme describes beliefs about the importance of an individual having autonomy over their life. This included that people should have the right to choose when to end their life, particularly when experiencing unbearable suffering and when it is felt that all other options for relieving this suffering have been adequately explored. Views that some people might feel 'ready' to die, either to avoid future suffering, and/or because life feels completed, and that assisted dying should also be acceptable in these situations were also shared. It was identified that a family member choosing an assisted death can be a challenging and emotional time, but that it is important to support a loved one in this decision, if it is what they want.

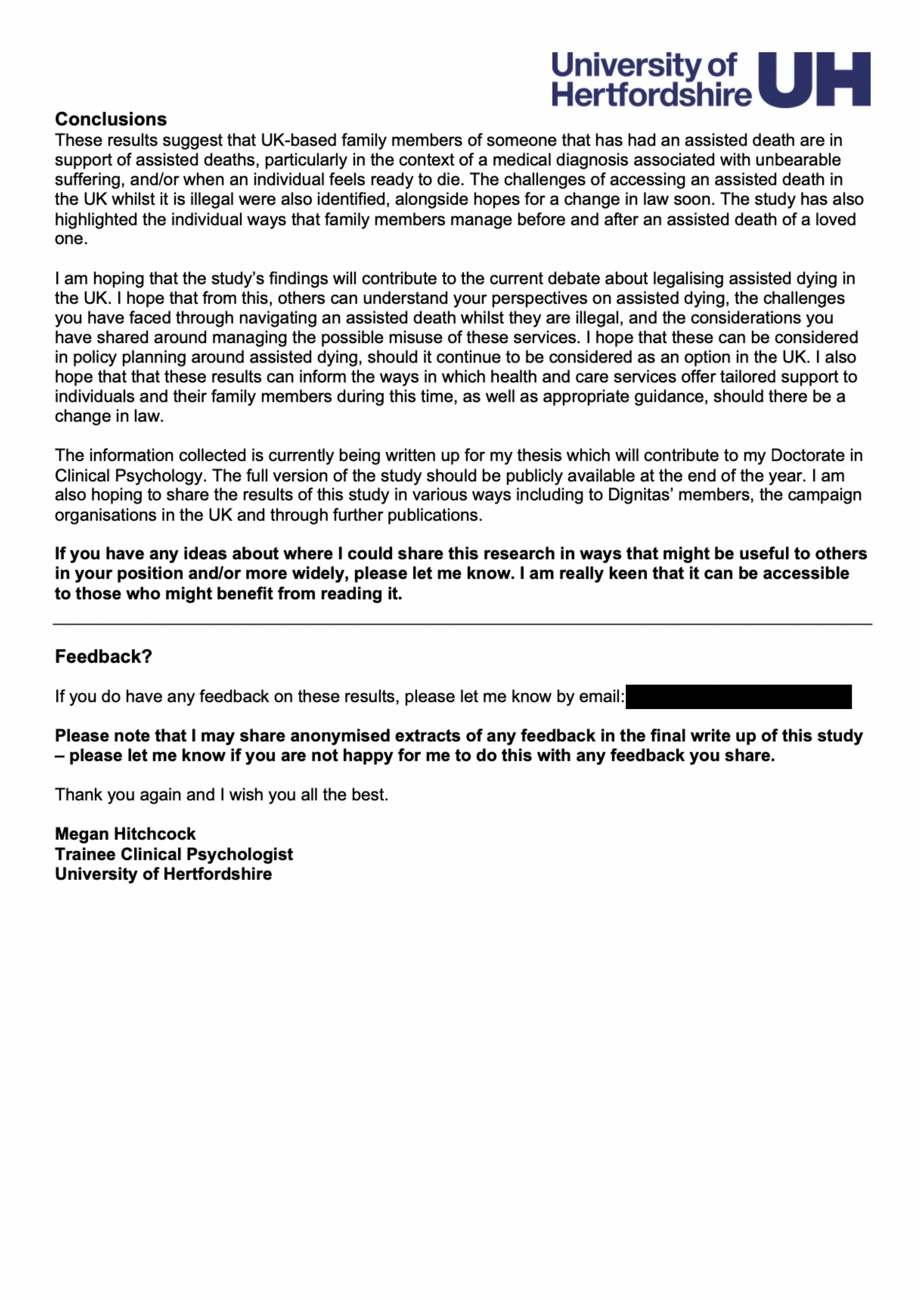
Theme 3: Navigating an "illegal" landscape

This theme focuses on experiences of navigating the assisted death journey with a loved one whilst it is illegal in the UK. Challenges were shared around needing to decide who this could be disclosed to. This seemed to be informed by the views of the family member having the assisted death, and/or worries about possible implications of telling others (e.g., their reactions and/or someone informing the police). The possible implications for medical professionals, if aware of the decision for an assisted death, were also considered. Some experiences with medical professionals were described as unhelpful, and the impacts of both sharing and not sharing with these professionals on everyone involved were acknowledged. This included views that being able to access guidance about the process would have been helpful.

Different ways of managing before and after the assisted death were described. This appeared to involve combinations of seeking support from close others (including the person seeking the assisted death before they died), maintaining life as usual or taking up new hobbies.

Theme 4: Assisted dying in the UK

This theme conveys positions on the current debate about whether assisted dying should be legalised in the UK. A change in law was generally supported, connected with views around the importance of individual autonomy and seeing assisted dying as part of progression within medicine. However, it was recognised that others, particularly those holding religious beliefs, may disagree. Issues around the possible misuse of assisted dying services were also identified. It was felt important that protocols to prevent misuse should be accounted for in relevant policies, but that these concerns should not prevent those seeking an assisted death from accessing one.



University of Hertfordshire UH

Conclusions

These results suggest that UK-based family members of someone that has had an assisted death are in support of assisted deaths, particularly in the context of a medical diagnosis associated with unbearable suffering, and/or when an individual feels ready to die. The challenges of accessing an assisted death in the UK whilst it is illegal were also identified, alongside hopes for a change in law soon. The study has also highlighted the individual ways that family members manage before and after an assisted death of a loved one.

I am hoping that the study's findings will contribute to the current debate about legalising assisted dying in the UK. I hope that from this, others can understand your perspectives on assisted dying, the challenges you have faced through navigating an assisted death whilst they are illegal, and the considerations you have shared around managing the possible misuse of these services. I hope that these can be considered in policy planning around assisted dying, should it continue to be considered as an option in the UK. I also hope that that these results can inform the ways in which health and care services offer tailored support to individuals and their family members during this time, as well as appropriate guidance, should there be a change in law.

The information collected is currently being written up for my thesis which will contribute to my Doctorate in Clinical Psychology. The full version of the study should be publicly available at the end of the year. I am also hoping to share the results of this study in various ways including to Dignitas' members, the campaign organisations in the UK and through further publications.

If you have any ideas about where I could share this research in ways that might be useful to others in your position and/or more widely, please let me know. I am really keen that it can be accessible to those who might benefit from reading it.

Feedback?

If you do have any feedback on these results, please let me know by email: [redacted]

Please note that I may share anonymised extracts of any feedback in the final write up of this study – please let me know if you are not happy for me to do this with any feedback you share.

Thank you again and I wish you all the best.

Megan Hitchcock
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University of Hertfordshire